FAMILY-CENTRED HEALING AT HOME:

A Samoan Epistemology of Samoan Families’ Experiences of Home Dialysis and Home Detention in Aotearoa/New Zealand

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ABSTRACT

Home dialysis and home detention are home-based public services increasingly used in Samoan households living in Aotearoa/New Zealand. They are cheaper than institutionally-provided hospital and correctional services and save the government millions of dollars; savings which do not seem to be transferred to the households which switch to home-based services. This thesis considers the role of housing in Samoan families living in Aotearoa/New Zealand, both symbolically and practically. It analyses in depth the way these two different public services are adapted within the home built environment and the effect these have on the lives of Samoan occupants.

The quality of housing and built environments are a vital and significant component of home-based services, yet, largely ignored in the literature and state policies as having an effect on the health of occupants. In this qualitative research I used a multiple-case study approach to investigate the housing experiences of five Samoan dialysis patients (n=4) and their carers (n=8); and two Samoan home detainees (n=2) and a sponsor (n=1). Using an iterative approach of the Photovoice method, disposable cameras were used by the participants to produce photographs about their experiences.

In consultation with Samoan elders, I also developed an epistemological model of Samoan health and well-being based on the traditional house and descriptions of tides and winds. The participants’ photographs and in-depth interviews in the Samoan and English languages were matched to the three stratified areas of the Samoan traditional dwelling: front of house, middle of house and back of house. Key informant interviews with public service officials were also analysed to provide important information about the Wellington Hospital Renal Unit (n=2) and the New Zealand Prison Services of the Corrections Department (n=5).

Home-based services, when compared to hospital and prison institutional services, gave the participants many advantages. These included the convenience of being at home, reduced transport and travelling costs, spending more time with family and
friends and in some cases participation in vocational and rehabilitation programmes. Samoan culture provided a useful framework for families to respond to the sensitive issues and obligations associated with palliative renal care, death, spirituality, gender arrangements, transplantation, cultural identity and restorative justice.

Other unexpected and less favourable outcomes associated with home-dialysis were fuel poverty, lack of indoor storage, minimal spatial heating and issues of waste disposal. Samoan participants expected far more support at home from public authorities than they in fact received and many of them experienced stigmatisation and social isolation. These everyday experiences forced some dialysis patients to give up home-based services and return to hospital services, which are more expensive. For some home detainees, spousal violence and problems with other family members increased because they were confined at home. They also failed to gain access to vocational and rehabilitation programmes.

Finally, while there was general agreement by participants that home-based services are a positive and effective way of increasing individuals' independence and freedom, greater improvement of home built environments as well as increased assistance from public authorities is needed so that families can better meet the formal requirements of home dialysis and home detention. The results, recommendations and the photographs produced by the participants were reported directly to the key governmental stakeholders supporting the study.
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# GLOSSARY, TECHNICAL DEFINITIONS, ABBREVIATIONS AND ACRONYMS

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<th>Definition</th>
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<tr>
<td>Ambulatory</td>
<td>Not confined to a bed, able or strong enough to walk: an ambulatory patient.</td>
</tr>
<tr>
<td>Chronic</td>
<td>Lasting for a long period of time or marked by frequent recurrence, as certain diseases: chronic colitis.</td>
</tr>
<tr>
<td>Morbidity</td>
<td>An illness or an abnormal condition.</td>
</tr>
<tr>
<td>Peritonitis</td>
<td>Inflammation of the peritoneum, often accompanied by pain and tenderness in the abdomen, vomiting, constipation, and moderate fever.</td>
</tr>
<tr>
<td>Primary care</td>
<td>Primary care is the care to which any patient can refer himself or herself. It includes but is not limited to general practice.</td>
</tr>
<tr>
<td>Secondary care</td>
<td>Secondary care refers to care carried out in most hospitals. This is the first port of call for patients who are referred by their GP except in certain circumstances when the GP may refer the patient directly to a tertiary centre.</td>
</tr>
<tr>
<td>Glomerulonephritis</td>
<td>An inflammatory disease affecting the clusters of capillaries glomeruli in the cortex of a kidney.</td>
</tr>
<tr>
<td>or kidney disease</td>
<td></td>
</tr>
<tr>
<td>diabetic nephropathy</td>
<td>Progressive damage to the kidneys seen in some people with long-standing diabetes. Excessive leakage of protein into the urine is followed by gradual decline of the kidney function and even kidney failure. See also diabetic glomerulosclerosis.</td>
</tr>
<tr>
<td>‘66% Rule’</td>
<td>The NZPS policy restricts eligibility to detainees who have served out at least two-thirds of their prison sentence; and prevents prisoners on short-term sentences (less than two years) from participating in in-prison programmes.</td>
</tr>
<tr>
<td>ACP</td>
<td>Interview during which treatment benefits, burdens, predicted prognosis and the patient’s preferences were discussed. Patients who preferred palliative care to dialysis were recruited into the rpc program. An interdisciplinary team approach was adopted and the renal palliative clinic comprised the core component among the full spectrum of services.</td>
</tr>
<tr>
<td>ANZDATA</td>
<td>The Registry records the incidence, prevalence and outcome of dialysis and transplant treatment for patients with end stage renal failure.</td>
</tr>
<tr>
<td>APD</td>
<td>An assisted form of dialysis in which the lining of the abdomen, the peritoneal membrane, acts as a natural filter.</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>C&amp;CDHB</td>
<td>Capital and Coast District Health Board</td>
</tr>
<tr>
<td>CAPD</td>
<td>Continuous Ambulatory Peritoneal Dialysis</td>
</tr>
<tr>
<td>CBS</td>
<td>Community-based sentences</td>
</tr>
<tr>
<td>CKD</td>
<td>Chronic Kidney Disease</td>
</tr>
<tr>
<td>CPPS/CPS</td>
<td>Corrections Community Probation and Community &amp; Psychological Services or Community Probation Services</td>
</tr>
<tr>
<td>CVD</td>
<td>Cardiovascular disease</td>
</tr>
<tr>
<td>EM</td>
<td>Electronic Monitoring</td>
</tr>
<tr>
<td>ESKD</td>
<td>End Stage Kidney Disease</td>
</tr>
<tr>
<td>ESRD</td>
<td>End Stage Renal Disease</td>
</tr>
<tr>
<td>ESRF</td>
<td>End Stage Renal Failure</td>
</tr>
<tr>
<td>GFR</td>
<td>Glomerular Filtration Rate</td>
</tr>
<tr>
<td>HHD</td>
<td>Home Haemodialysis</td>
</tr>
<tr>
<td>HSU</td>
<td>Haemodialysis Satellite Unit</td>
</tr>
</tbody>
</table>
The patient takes full responsibility for delivering dialysis treatment, or serviced, where a staff member or members are present to support patients to receive dialysis treatment.

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICHD</td>
<td>In-Centre Haemodialysis</td>
</tr>
<tr>
<td></td>
<td>Haemodialysis treatment, usually received at a hospital renal centre for kidney failure, in which the blood passes through an artificial dialyser to remove wastes and water.</td>
</tr>
<tr>
<td>IOMS</td>
<td>Integrated Offender Management System</td>
</tr>
<tr>
<td></td>
<td>An information data system that provides details and background of an offender convicted in a New Zealand prison.</td>
</tr>
<tr>
<td>PD</td>
<td>Peritoneal Dialysis</td>
</tr>
<tr>
<td></td>
<td>Can be CAPD or APD.</td>
</tr>
<tr>
<td>RoC*RoI</td>
<td>Risk of Re-Conviction*Risk of Imprisonment</td>
</tr>
<tr>
<td></td>
<td>An assessment tool used by the Department of Corrections to predict the propensity of reoffending.</td>
</tr>
<tr>
<td>RPC</td>
<td>Renal Palliative Care</td>
</tr>
<tr>
<td></td>
<td>A renal palliative care (RPC) program was developed in a local centre as an option for patients with end-stage renal disease (ESRD) who may not benefit from dialysis or who do not prefer dialysis.</td>
</tr>
<tr>
<td>RRT</td>
<td>Renal Replacement Therapy</td>
</tr>
<tr>
<td></td>
<td>Renal replacement therapy is a term used to encompass life-supporting treatments for renal failure.</td>
</tr>
</tbody>
</table>
# GLOSSARY OF SAMOAN AND MĀORI TERMS

<table>
<thead>
<tr>
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<th>Meaning</th>
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<tbody>
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<td>family</td>
</tr>
<tr>
<td>aiga potopoto</td>
<td>extended family</td>
</tr>
<tr>
<td>aitu</td>
<td>ghost, spirit</td>
</tr>
<tr>
<td>aumaga</td>
<td>Formal village organisation of untitled men.</td>
</tr>
<tr>
<td>autalavou</td>
<td>young people</td>
</tr>
<tr>
<td>aganu‘u</td>
<td>Customs and traditions adhered and practiced in Samoan villages.</td>
</tr>
<tr>
<td>ali‘i ali‘i</td>
<td>chief</td>
</tr>
<tr>
<td>alofa</td>
<td>love</td>
</tr>
<tr>
<td>ataata</td>
<td>image, picture</td>
</tr>
<tr>
<td>atunu‘u</td>
<td>nation</td>
</tr>
<tr>
<td>aualuma</td>
<td>Formal village organisation of married and unmarried women.</td>
</tr>
<tr>
<td>efuefu</td>
<td>ashes, earth, soil</td>
</tr>
<tr>
<td>ekalesia</td>
<td>congregation</td>
</tr>
<tr>
<td>‘emo’emo</td>
<td>light, flash, shining</td>
</tr>
<tr>
<td>fa’aafetai</td>
<td>thank you</td>
</tr>
<tr>
<td>fa’aaloalo</td>
<td>respect</td>
</tr>
<tr>
<td>fa’alavelave</td>
<td>Special events and experiences within a family or community that require the exchange of cultural gifts and Samoan traditions e.g. funeral, wedding, conferment of a chief’s title.</td>
</tr>
<tr>
<td>fa’alupega</td>
<td>Honorifics of a village</td>
</tr>
<tr>
<td>fa’amagalo</td>
<td>to forgive, pardon</td>
</tr>
<tr>
<td>fa’amatai</td>
<td>The heirarchacal structure of matai/chiefs and orators.</td>
</tr>
<tr>
<td>fa’asamoa</td>
<td>Samoan customs and traditions</td>
</tr>
<tr>
<td>feagaiga</td>
<td>Status given to a sister and through her all her descendants.</td>
</tr>
<tr>
<td>toe</td>
<td>paddle, spear</td>
</tr>
<tr>
<td>gafagafa</td>
<td>genealogy</td>
</tr>
<tr>
<td>galuā</td>
<td>wave or of the tide</td>
</tr>
<tr>
<td>ie</td>
<td>sheet, covering, mat</td>
</tr>
<tr>
<td>ivi</td>
<td>a bone; keel of a canoe</td>
</tr>
<tr>
<td>malae</td>
<td>open field which marks the main gathering areas within a village</td>
</tr>
<tr>
<td>ofe ofe</td>
<td>bamboo, object made of bamboo such as a cup or stick</td>
</tr>
<tr>
<td>oli oli/olioli</td>
<td>joyful; the name of a tree</td>
</tr>
<tr>
<td>olo</td>
<td>to whistle</td>
</tr>
<tr>
<td>oloa</td>
<td>masculine gifts like food, cattle, and plants</td>
</tr>
<tr>
<td><strong>osi osi</strong></td>
<td>devotion, caring; to sacrifice</td>
</tr>
<tr>
<td>--------------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td><strong>tala le faia</strong></td>
<td>genealogical connections</td>
</tr>
<tr>
<td><strong>tautua faiupu</strong></td>
<td>service of communication</td>
</tr>
<tr>
<td><strong>tautua matapalapala</strong></td>
<td>service of harvesting</td>
</tr>
<tr>
<td><strong>tautua matavela</strong></td>
<td>service of earth oven/umu</td>
</tr>
<tr>
<td><strong>tautua toto</strong></td>
<td>service of blood; to defend and protect one's family</td>
</tr>
<tr>
<td><strong>tautua va tapuia</strong></td>
<td>service of prayers and fire hearth</td>
</tr>
<tr>
<td><strong>tino rangatiratanga</strong></td>
<td>Māori term for sovereignty and self-determination as stipulated in articles 1 and 2, Te Tiriti-o-Waitangi.</td>
</tr>
<tr>
<td><strong>toga</strong></td>
<td>feminine gifts such as land and fine mats</td>
</tr>
<tr>
<td><strong>tulutulu</strong></td>
<td>Eaves of a Samoan house/fale made of thatching</td>
</tr>
<tr>
<td><strong>ufiuufi</strong></td>
<td>The act of embracing, concealing; yam or vegetable root.</td>
</tr>
<tr>
<td><strong>uga</strong></td>
<td>a soldier crab</td>
</tr>
<tr>
<td><strong>ulu</strong></td>
<td>head</td>
</tr>
<tr>
<td><strong>uso</strong></td>
<td>a brother's brother or a sister's sister</td>
</tr>
<tr>
<td><strong>va tapuanu'ua</strong></td>
<td>The period referred in Samoan history distinctly defined before the arrival of Christianity which was dominated by indigenous paradigmatic beliefs and customs over hundreds of years.</td>
</tr>
<tr>
<td><strong>va tapuia</strong></td>
<td>The sacred order of relationships that exists between human beings one with another, and their natural environment.</td>
</tr>
<tr>
<td><strong>whakapapa</strong></td>
<td>Māori word for genealogy</td>
</tr>
</tbody>
</table>
PREFACE

Perspectives of a Pacific woman in a Māori and Pacific landscape

Carried by icy southerly winds in April’s unpredictable east to west currents, we awoke to the hammering boom of the sting ray’s tail dredging The Narrows\(^1\) in Raukawa’s\(^2\) ocean; the majestic blackness of the monster somersaulted high, hitting the hard surface of the water before diving back to the depth above beds of crushed shells and coral bone. Without delay, the fai pe’a (stingray) in graced flight, chants first the remnant presence of the old ones below, lingers a calculated deliberate ascent, while the pervasive, yet familiar threat of Maui’s hook awaits.

A short distance round at Tarakena (Seatoun), the fishing hook transforms Kupe’s fist as weaponry might against Te Wheke-o-Muturangi\(^3\): the monster he unceasingly pursued from Hawaiiki, and again pursued out of refuge when he drove it from the cave at Rangiwhakaoma.\(^4\)

Upon the beach, in the dream, I too am running with the others towards higher ridges in desperate escape from the pelting tides discharged by Te Upoko o Te Ika (The Head of the Fish)\(^5\); am breaking free of the terrorised thrashes of Te Wheke (The Giant Octopus).

Forever in the foreground and covering Taputeranga (Island Bay), the reverberated boom of Kupe’s brawl with the monster; forever and all around the stained purple ochre of Pariwhero\(^6\) and the towering cliffs of Te Rimurapa, the defiant uproar of Maui’s sting ray.\(^7\)

A few days later, in a car driving to the south-west coastline of Te Whanganui-a-tara\(^8\), the ferocious scenes of the sting ray, plays out once again at high-tide; dredging forward silhouetted memories and glimpses of preHistory\(^9\) and preTreaty; while I, a Samoan within a Māori landscape become enveloped by the encountering of the city, its embodied whakapapa\(^10\) and gafa\(^11\).

---

1. The Narrows is a sea channel between the Marlborough Sounds (top of the South Island and the Makara Hills bottom of the North Island). Most of the Maori original name places were referenced from Adkin’s book and Wellington City Council’s Nga Waahi Taonga O Te Whanganui a Tara, Maori Inventory Sites.
2. Cook Strait channel that runs between the North and South Islands of Aotearoa/New Zealand.
3. Muturangi
4. Rangiwhakaoma (Castlepoint) on the Wairarapa coast, Ana o te Wheke a Muturangi.
5. Te Whanganui-a-tara or Te Upoko O Te Ika is the Wellington coastline and harbour area. Aotearoa/New Zealand’s capital city.
6. Pariwhero: Red Rocks – the pillow lava coloured purplish red, stained by Kupe’s daughters/nieces who cut themselves mourning Kupe’s death; is also the staining blood of Kupe’s baiting of the hook that captured Te Wheke.
7. Te-Ika-A-Mauri the North Island fished up by Maui, the mouth of the fish is Te Whanganui-a-tara, Wellington. Maori lore holds the fish to be a Stingray.
8. Wellington.
9. The settlement of Whanganui-a-tara encompass the following Maori Tribe and Iwi: Waitaha, Te Tini o Mamoe, Ngai Tara, Ngati Mamoe, Ngati Tahu, Ngati Ira, Ngati Mutunga and Te Atia Awa.
10. Whakapapa (Genealogy).
Many of us grew up here. The geological formations of Te Whanganui-a-tara (Wellington) align Māori and Pacific universally; it’s easy to acknowledge here that we have descended from ‘fished up’ islands, stamping earthquakes and spewing volcanoes (1).

For decades our Pacific families have crowded to the bays and dunes of these Wellington beaches (2). It is here at Mākarā, Owhīro, Taputerānga (Island Bay), Haēwai (Houghton Bay), Huē-te-para (Lyall Bay), Kirikiri-tātāngi (Seatoun), Matāa-iwi (Eastbourne), Orūa-mōtoro (Days Bay) that I was inspired. Even today, at every first sailing across Raukawa (Cook Strait) paying careful observance of Kupe’s nieces, Matiu (Somes Island) and Makaro (Ward Island); and then near Pariwhero, at the rocks named Ngā Whātu, looking away discreetly, is a sign of respect for the Stingray’s permanent resting place.\(^{12}\)

Perhaps it’s because my family frequented there often in the 1960s, ’70s and ’80s for paūa (abalone) and kina (sea eggs) that Pariwhero (Red Rocks) and Te Rimurapa (The Bull Kelp)\(^{13}\) are happy places of childhood. Not only the bull seals and forest rimurapa slumbered there on sunny days. We too can testify to the importance this Pacific place has in warming us.

These are beaches of beauty, even if at the turning of the tide their waters become restless and treacherous; even if Wellington’s infamous hurricanes bear down; there is something metaphorical about these beaches and their unpredictability (3); something reminiscent of the havoc wreaked by the all too frequent cyclones that roam our own Pacific Sea of Islands (4). Like the waters that surround us there, the seas here in Aotearoa are also cleansing, healing waters for many of us.

---

11 Gafa: Samoan term for genealogy.
12 I remember my Māori teachers at Te Aro Primary School and Wellington East Girls’ College telling us about being careful when travelling across on the Cook Strait Ferry, not to look out past the Red Rocks because there was ‘something’ like a taniwha there! (A taniwha is a is giant monster Māori mythology)
13 Te Rimurapa is the location site also known as Sinclair Head.
To bathe in these waters and to stand in the wind’s shadows is a blessing for the attainment and daily remaking of *tino rangatiratanga*\(^{14}\); what greater than this could we offer?

It was inevitable that the ocean waters and the winds that surrounds *Te Whanganui-a-tara* would influence various aspects in which this doctoral study was conducted and the areas of interest that were explored.

From the period Samoans first encountered Europeans within Pacific Ocean territories, the classificatory typologies labelling the Pacific person has undergone endless reconstructions and continues into contemporary times. The term ‘Oceania’ is derived from the early French navigators’ journals describing European encounters with Pacific peoples. ‘Pacific’ is defined accordingly as the small Pacific Island states and territories of Polynesia and Micronesia (4). Many hours, days and years I have sat and looked out at this beautiful south coast to find inspiration and hope from those who journeyed across *Te Moana-Nui-A-Kiwa* (Pacific Ocean); because in their likeness we too are navigators of rough storms and countless battles. Samoa, we too have our own ocean monsters and turbulent winds; our walless buildings, at front, at back.

What the world should now well know about all Pacific peoples is that we come from great lineages and so follows the significance of Naming.

It is not that we hope our children will be great navigators; it is that we expect them to be.

\(^{14}\) *Tino rangatiratanga*: sovereignty and self-determination as stipulated in Articles 1 and 2, Te Tiriti-o-Waitangi.
Map 1 of the Pacific Islands, showing the main islands and island groups indicating the earliest known time of initial human settlement. Source: Nunn, 2003
INTRODUCTION: THE LINK BETWEEN HOUSING, FAMILIES AND THE STATE

1.1 Purpose of this Thesis

The title of this thesis, ‘Family-centred healing at home’ is designed to reflect the strengths of Samoan families who provide care and support for loved ones in receipt of highly regulated services, technical equipment, professional expertise and publicly-funded arrangements within the home setting. Housing and the built environment are presumed in this thesis to have an impact on the day-to-day life experiences of two distinct family groupings: ‘dialysis patients’ and ‘home detention detainees’.

Very little is known about Pacific families’ life experiences while undergoing renal home dialysis therapies and home imprisonment. One thing that is clear is that individuals with chronic illness, their carers and those incarcerated within the criminal justice system are amongst the most vulnerable of our Aotearoa/New Zealand society (5-7).

Home-based public services provide an important and viable solution in offsetting the high costs of institutional services nationwide and therefore offer some attractive incentives and alternatives to institutional hospital and prison services. Yet, Pacific peoples tend not to gravitate towards them despite their low cost, entitlement and availability. On many different levels, home dialysis and home detention are two very dissimilar services; however, they are linked inextricably by two important factors: that (Samoan families and Samoan homes) formal obligations save resources and money for the state.

One of the ironies that bring two seemingly different services together is that home detention evolved from equipment, which was originally designed to determine the whereabouts of psychiatric patients within an institutional setting; and not necessarily for the purposes of deinstitutionalisation (8-10). Whilst, home dialysis has been available for nearly four decades and home detention for one and a half decades in New Zealand; little is actually known about the way that Pacific families experience
their homes as places for publicly-funded services. This qualitative thesis explores some of the important, less known and recognised factors related to home-based services and community sentencing about these two subjects. This thesis also provides new insights about the phenomena of home services, particularly from the perspectives of Pacific migrant families who have established themselves in New Zealand since the post-Treaty mass migratory arrivals of the 1950s, 1960s and 1970s. ‘Home’ as told by the stories of the families in this study is more than a building or a house; it is a place for healing, growing and dying.

1.1.1 Key questions and focus

This doctoral study is a qualitative investigation about Samoan peoples’ housing experiences, which focuses on six key questions:

- What are the housing experiences of Samoan people in receipt of home-based dialysis and home detention services in Wellington?
- What is the impact of the built environment on the health and well-being of Samoan families?
- If the goals of the District Health Board and the Department of Corrections are to increase the health and justice outcomes of Samoan families, how are they being met?
- How do Samoan families cope with the structural barriers of the built environment while carrying out the formal obligations associated with home-based services?
- What involvement does the state have in the lives of Samoan families - is it too involved in the life of its citizens?
- What impact do home-based services, supervised by the State, have on health inequalities and social disparities experienced by Pacific families in Aotearoa?

1.2 Pacific Families

The Pacific diaspora and the mass migrations of the 1950s, 60s and 70s are part of the housing background for Pacific peoples that make Aotearoa one of the most multi-cultural nations of the world. The Pacific population is expected to grow to 480,000 by 2026 (11) and to 600,000 by 2051 (12). Samoans are the largest of the
seven main Pacific population groups\textsuperscript{15} in Aotearoa/New Zealand, totaling 131,103 in 2006; the majority of whom are living in extended families.\textsuperscript{16} Currently, 56% of all Samoans are under the age of 15 years old, a distinctive demographic pattern in New Zealand society (13).

\textbf{1.2.1 Samoan cultural identity formation}

For several decades, focus on the alteration, modification and preservation of Pacific customary practices has been documented in the lives of those living both in their nation of origin and diaspora communities (14-16). Preferences to live with extended family members have been long documented as a common feature of Pacific households in Aotearoa/New Zealand.\textsuperscript{17} In 1996, 41% of Samoan households were made of two generation and 58% were made of three generations extended families that typically included a grandparent and at least one grandchild. In 2001, 29% of the Pacific population reported living in extended families compared to eight percent of the rest of New Zealand, although this increased quite markedly in 2005 to 41% and 14% respectively (17).

Families are an essential physical, emotional, spiritual, financial, cultural and social resource for New Zealand citizens. There are an estimated 6,800 Pacific people in this country who suffer long-term chronic disease and disabilities and they were twice as likely to be cared for at home by an informal carer, a person likely to be an adult family member (18). For many Pacific families, ‘carers’ are also the most vulnerable within families: young women, children and elderly spouses (19).

Cluny and La’avasa Macpherson describe the pattern of “cultural and structural pluralism” that emerged and helped Samoan communities to preserve and maintain their own identities and institutions to cope with the rapid New Zealand urban industrial environments (20). Structural factors such as residential and occupational

\textsuperscript{15} Cook Islands Māori (including Rarotongan etc) 58,008, Tongan 50,481, Niuean 22,476, Fijian 9,864, Tokelauan 6,819 and other Pacific groups 8,907.

\textsuperscript{16} Extended families are defined as: This may include more than one set of related parents, their children and/or grandchildren. As at 1996, 58% of all Samoan family households in New Zealand were third generation types and 41% two generation types (both types include a grandparent and at least one grandchild).

\textsuperscript{17} An extended family is a group of related persons who usually reside together and consists of: a family nucleus and one or more ‘other related persons’, or two or more related family nuclei, with or without other related persons. People who usually live in a particular dwelling, and are members of an extended family in that dwelling, but who are absent on census night, are included, as long as they are reported as being absent by the reference person on the dwelling form. (Statistics New Zealand, 2006).
concentrations; extended kin groups; remittances back home to Samoa; natural disasters and crop failures; savings and loan associations helped to continue loyalties and mobility between New Zealand and Samoa-based Samoans (p. 71).

In a study following 250 people with kinship, ties over a period of 10 years the Macphersons also investigated factors that influence New Zealand-born Samoans constructions and orientations of ethnicity (21). They found that young people are greatly influenced by environments where Samoan parents and other adults implicitly, ambivalently or explicitly promoted and criticised Samoan culture (p.113). These factors have significant bearing on decisions about the care of dependent family members and eventually the functional uses of the house for household activities.

An important area of investigation for the dialysis and detention studies focused on the underlying beliefs and practices families employed to cope with the complexities associated with chronic illness and incarceration. As will be shown in the results chapters, both Samoan culture and Christianity play an integral part in household behaviour and decision-making.

American anthropologist, Margaret Mead after spending nine months in Samoan villages during the mid-1920s described Samoans as having an, ".... aptitude for manipulating ideas, and moving things and persons about in a schematic and ideal chess board..." (22). Impressively, Mead who was in her early 20s when she made those observations captured something unique about the complexities of Samoan traditional society. These complexities are underpinned by Samoan epistemologies formed by observations of the natural environment; observations which became strategies used by Samoans to interpret and understand their life experiences.
1.3 Samoan Epistemological Approach

Several years ago, I completed my Master’s thesis about ten Taulasea (traditional healers) indigenous healing practices. What they reported was that they had treated approximately 1020 patients (mostly Samoans) in Wellington between 1994 and 1995 (23). These patients adhered strongly to Samoan indigenous notions of health and wellbeing, while also accessing the formal primary and secondary health services, distinguished otherwise as Western medicine. An important finding, which in part influenced the development of my doctoral study, was the importance of the family home as a place where a range of ‘formal’ and ‘informal’ Samoan protocols are exchanged between one family (the Taulasea’s family) and another family (tagata ma’i, the patient’s family). These exchanges are important because they facilitate the reciprocation of goods and services in the form of cultural feminine and masculine wealth (toga and oloa); but more importantly, they assist families to generate insights and potential solutions to issues related to their health and wellbeing.

In this doctoral thesis, I ventured further by exploring the traditional housing concepts and considered the spatial divisions of roles and responsibilities normally carried out within the Samoan fale/dwellings. I did this by collecting cultural knowledge of Samoan tides and winds, which are normally the preserve of Samoan orators (24-26); environmental indicators and metaphorical images that Samoans traditionally used to understand the way that power, status and authority are mediated between individuals, families and organisations. The divisions of responsibilities are extremely well defined within Samoan society as those which normally belong at the ‘front of house’ (formal interactions with those within and outside of Samoan society) and ‘back of house’ (informal and domesticate activities). For the purposes of this thesis, I have attributed ‘middle of house’ as that which is associated to all things ‘culturally’ important within Samoan society. An area of interest for the study was to examine the extent to which the families in associate their every-day experiences at home within these three stratified divisions of recognised in Samoan society and how these in turn are associated to the physical and social proximal spaces of their houses and homes. Secondly, metaphorical concepts derived from Samoan oratory, can help provide unique analyses of Samoan families’ day-to-day experiences, and
potentially contribute to understanding chronic illness and incarceration in Aotearoa. Linking the metaphorical representations of Samoan traditions with the participants’ experiences, enabled me to illuminate a range of sensitive and complex situations that are not normally seen in public or by those on the ‘outside’.

The epistemological framework for this study attempts to challenge the misconceptions and stigmatisation associated with Pacific peoples as being helpless and incapable of dealing with the complexities of modernisation. As Howe’s survey of Pacific historiography and literature of the 1800s and 1900s showed, the dominance of European romanticised views depicted Pacific peoples as falling into two distinct categorisations: those who would not withstand the impact of Western modernisation and those who would survive them; these analysis Howe states, still continue (27).  

This thesis attempts to highlight the structural associations of disease and treatment, but also highlights aspects that support and make it more difficult for families to cope with chronic illnesses and incarceration.

1.4 The Primacy of Home

The literature about home dialysis and home detention avoids several critical factors that might be reasonably considered important for publicly provided home-based services. Housing stock availability, housing condition, location, structure and market prices seem not to feature at all, despite the direct and indirect impacts these would have on peoples' lived experiences: “Depending on the jurisdiction, both local and central governments have an important role in regulating housing sustainability, including health outcomes” (p.5) (28).

The primacy of “home” and “place” became a focus for the renal services sector almost 40 years ago, in the recognition of the projected economic burden that the public health system was expected to respond to at all levels through the increased rates of non-communicable diseases such as diabetes mellitus II, hypertension and cardio-vascular disease. Around the same time, developments within the criminal...
justice system, particularly over the last two decades focussed similarly on finding alternative measures to the burden of institutional imprisonment. Home dialysis safeguarded the home for health-based services, while home detention, or the electronic surveillance of offenders, fortified the family home as a primary site for community-based sentences. In the following sections, I describe briefly the current levels of housing stock availability in Aotearoa and highlight some important barriers associated with the indoor environment and its relevance to home-based services.

1.4.1 Housing as a determinant of health

Housing and the indoor built environment is a key determinant of health; housing in its own right can influence the health of the occupants (29-51). Dunn highlights the role housing plays in the vulnerability and health of families:

...housing is much more than just such a lens: it is also a nexus for the operations of unequal social relations and a medium through which socio-economic status is expressed and through which a wide range of known health determinants operate. These forces may be especially influential on the health and functioning of vulnerable and marginalised groups in society (e.g. seniors, children, people with disabilities and chronic illnesses, aboriginal groups) (pg. 14) (43).

Housing can also have an impact on the occupant’s mental health (52, 53). There is little literature on the effect of external agencies on home life of families in general, or Samoan families in particular. Although, when health and social services are integrated to improve homes, households whose homes have been improved feel better able to participate in housing decisions (35).

The links between indoor temperatures on the health of household occupants has several implications, especially in older and colder houses. New Zealanders, as in many countries of the OECD spend most of their time indoors (72-73%); people with chronic illness spend 90% of time inside (29). This is important given that a person’s lived experience of a home-based service is influenced by what happens within the indoor built environment.

In Aotearoa/New Zealand there were about 900,000 houses built before 1978 that were not insulated; this means that the average winter temperature in New Zealand
homes is 16°C, when the World Health Organization recommends 18°C – 21°C. Many Māori and Pacific people rent and live in older houses like these which have no insulation, are damp, cold and mouldy (30, 42, 54, 55).

In a cohort study of patients’ residential areas by Telfar Barnard and colleagues, there was an eight percent excess winter mortality of those who were hospitalised or died with respiratory and circulatory conditions during winter. This based on the unique patient identifier, the National Health Index linked all dwellings to hospitalisation records and showed that these were mostly people who resided in ‘older’ houses. Interestingly, it showed that Pacific peoples had a significantly higher rate of hospitalisation, which suggested a causal link to the older and potentially colder houses that they occupied (49).

Baseline studies of two community trials with nearly 2,000 households from seven low income settings, which was conducted by He Kainga Oranga/Housing and Health researchers, found that 65% of the occupants reported being cold "all" or "most of the time"; and Pacific households that were surveyed said that they “often felt cold” in their houses (56). After the indoor environment was improved by insulation and effective heating appliances, the houses were warmer for the participants. The consequence of warm houses showed some improvement of health, which was demonstrated by fewer visits to the doctor and less absenteeism from work and school (30, 40, 41, 57).

The ability to keep one’s home warm can be more difficult than it sounds. Some families within the most deprived communities are concerned about warming their homes and are faced with the constant fear of accruing fuel debt from electricity and gas payments (58). An increasing number of households choose ‘pre-payment’ electricity formats because they believe them to be ‘cheaper’ and more affordable; in fact, prepay formats over the longer-term period prove more expensive (56). Another way that families cope with fuel debt and fuel poverty is to voluntarily disconnect their electricity and not spend the necessary amount of money for indoor warmth; either way these are preferred options because they are cheaper ways to live (59).
The indoor climate of houses can be extremely difficult for elderly people with chronic illnesses who are ‘aging in place’ (39). Within a largely fragmented housing sector which is unprepared to incorporate accessibility renovations to new buildings (36, 37). Pacific individuals and their families can experience on-going barriers which hinder their choices of housing that will support them to live independently with complex physical and sensory impairment and disabilities (60). As will be shown in the results of my dialysis and detention studies, structural barriers within the built environment became increasingly important factors in household decisions.

1.4.2 Housing availability for families

People with chronic kidney disease and prisoners sentenced to home imprisonment, experience major difficulties with securing both short-term and long-term accommodation. The extent to which home-based public health and community-based imprisonment sentences leads to greater interference in the lives of individuals and their families is an additional and significant issue in relation to housing experiences for these two vulnerable population groups.

A survey of New Zealand’s current housing stock shows that it is not able to meet the high demand for accessible and affordable housing associated with the rapidly aging population and higher survivor rates among those affected by disabling injuries, conditions, or illnesses (37). The majority of disabled people live in houses, not designed with suitable accessibility, and many experience stress in having their homes modified through state-funded arrangements (37). While state housing authorities provide some assistance, the increasing demands from families who support their loved ones with complex health and imprisonment issues become heightened given the increasing numbers of Pacific families living in socio-economically poor circumstances.

In New Zealand, the private rental sector provides 88% of rental properties, the remainder are provided by central and local government. This includes 14,036 (1%) rental dwellings provided by local council authorities nationwide, mostly occupied by elderly and disabled tenants (36). HNZC is the main government provider and owns
69,000 properties (12% of rental stock) while 5,000 dwellings was provided by non-for-profit ‘third sector’ providers (61).

Finding adequate affordable housing can be difficult in any circumstances because of the major shortfall of nearly 70,000 properties in the housing market; an estimate that is expected to rise, particularly in the Auckland region, to a projected shortfall of 90,000 by 2031 (62). In 2012, based on housing construction volumes the Productivity Commission predicted a shortfall of 15,000 dwellings between 2011-2016 (63).

1.4.3 Housing and the poverty trap for Pacific families

Housing ownership is often associated with a higher standard of living and increased disposable income. While most households own their own homes, only 22% Pacific (all ethnicities) and 23% of Samoan households in 2006 owned the dwelling that they lived in (13). The rate of ownership nationwide has fallen over the last two decades from 74% in 1991 to 67% in 2006 (64). Pacific home ownership increased slightly to 25% in 2009, but most Pacific communities (58%) were renters in 2007 (47). Pacific made up almost a third (31%) of those who rent from a private landlord: 15% lived in accommodation as boarders and 27% were HNZC tenants (61).

Historically Pacific peoples have been long-term tenants of state housing. The current HNZC policy emphasis is that, “We provide affordable housing for those in greatest need, for as long as they are in need” (61). This may change, as the government is working to shift tenants’ perception, that a “state home is a home for life”. It is a somewhat spurious goal, given that most people living in state and social housing properties are already amongst those with greatest needs.

Grimes and colleagues investigated the way in which housing is a “fulcrum” of economic and social outcomes for individuals and households (65). After cross-analysing tenancy rental data, house prices, deprivation measures and census data between 1996 and 2001 they found that families living in more deprived locations tend to pay higher rental costs; and that renters tend on average to occupy older houses needing repairs than owner occupied houses (p. 75). The authors
highlighted that the relationship between rentals and deprivation locations has dire consequences of “potential poverty traps” and “wealth disparities”. This has major implications for Pacific communities who are predominantly long-term renters and occupy a majority of deprived urban city locations.

In 2001, 42% of Pacific people lived in the 10% most deprived small the 2006 (66). Census shows the formation of ‘older households’ as an important trend within the housing sector, as more people choose to stay living at home longer, rather than leaving to set up flats and new households (60).

With greater numbers of people in larger families living longer at home, the issue of sufficient household space has been a major problem for Pacific communities, because many New Zealand houses were originally designed and constructed for less occupation. The need for additional household living space was reported for about 43% of Pacific households live in ‘severe crowding’ conditions (according to the Canadian National Occupancy Standard), requiring at least two additional bedrooms in the house that they were living in (64).

Families living in standard HNZC properties can often experience shortage of space within dwellings, which leads to crowding, and the potential risks of infectious diseases (67). Because of income-related rents, those living in HNZC properties usually have more disposable income than they would have living in private rental accommodation. Some of the important advantages for extended families living together are that they can reduce the costs of household expenses and share specific household duties and responsibilities (47). Families with younger dependents experience greater economic and social challenges compared to those where there are a greater number of adults working within a family (47). This pattern has significant implications on household decision-making. Figure 1.1 shows that the scale of hardship is higher for a family with young children.
Figure 1-1 Exploring Housing Options for Pacific Families. Based on Standard of living (Economic Living Standard Index 2005, Ministry of Social Development. Source: Ministry of Pacific Island Affairs, 2009).

One of the unknown issues for families caring for those on home dialysis and home detention is the extent to which formal obligations of care generate greater household expenses and how this affects housing experiences. In my study, I examined the potential solutions, which families applied in response to issues of social and economic hardship.

An area of severe hardship within families is the rates of family violence and offending. The home setting is a place where 47% of criminal victimisation by Pacific peoples is experienced (64). According to the Family Violence Database held by the Families Commission, 10% of reported cases were by Pacific offenders (68). Similarly, at least 12% of all police apprehensions were offences by Pacific involved mostly in family violence situations within the home setting (68). For male-assault-female convictions in 2006, 12% were Pacific; Pacific men and 1% by Pacific women carried 19% of assaults of a child. Pacific and Māori men are largely responsible for high rates of hazardous drinking, which, consequently contributes to other forms of
social disorder within Pacific communities (48). These can include breached protection orders of which Pacific men committed seven percent. In consideration of families who have to manage issues of violence and victimisation at home, the formal mechanisms, such as restorative justice and external assistance from state and civil organisations become increasingly important. This became an area of discussion for my study within families, particularly amongst the home detention families although other important issues such as stigmatisation and reintegrating within one’s respective communities were shared themes associated to both home dialysis and home detention.

1.5 Home Dialysis

1.5.1 The home as a place of ‘universal health care’

Over the 1990s and 2000s, the exponential rates of obesity and diabetes amongst Pacific and Māori patients requiring dialysis treatment, became the focus of attention (69-71). “Home-based” dialysis treatment, renal physicians argued, needed to resolve “complex health problems” through “stronger community-based help”, through the integration of secondary and primary health services (p.232) (72). "Our philosophy is everyone can do it at home unless it is shown they can't. The country has been able to keep people dialysing at home because of the attitude of staff, good support from GPs and the community" (p.15) (73). The first national Renal Replacement Therapy (RRT) service for patients with chronic kidney disease was opened in 1969 as the Christchurch Home Dialysis Training Unit (69).\textsuperscript{19} This was the start of the era where home dialysis was extended as the ‘national home dialysis service’ and became a permanent feature within New Zealand homes.

New Zealand has always operated a universal home dialysis service for its citizens. By the time the devolution of the Disability Support Services Framework of the mid-1990s arrived (70) the ‘patient’s place of residence’ for dialysis therapies had been operating for several decades nationwide. Crown entities emphasised the shift of funding from ‘state to community’, by devolving health resources and contract

\textsuperscript{19} In January 1982, the Department of Health Hospital Division, Wellington, circulated the Electrical Wiring Regulation, 1976, Memorandum No. 4, authorising the Electrical Safety Requirements for installing a dialysis machine as a “medical appliance,” within the home of a patient for the purposes of renal replacement therapy (RRT).
purchases between public, private and voluntary agencies, achieved in part by shifting centralised services to regional and area health boards (74-76). This involved major cuts and downsizing across the health sector such as the reduction of non-clinical services, administrative personnel, maintenance, and costs of hospital meals, clinical laboratory and diagnostic services.

Unlike other hospital facilities that faced closures and downsizing, the public health renal services continued to maintain services “at the same level”. This was largely because medical equipment had “declined in cost” (77) and partly because of the eligibility criteria, which excluded certain groups of patients from receiving dialysis on the grounds of age and medical fitness (78).

It was during the late 1990s, in the midst of the radical health reforms when the New Zealand renal services were at the fore of public health debates about ‘rationing’ and ‘priority setting’. The provision of dialysis treatment became a major public concern and patient-led legal court cases challenged the powers of the district health boards to refuse medical treatment on the eligibility criteria of the period (71, 74).

An important review by the Government Tertiary Services Review Committee in 1995, allowed dialysis treatment for all patients regardless of age and also identified key priorities for the improvement of existing support services in relation to kidney organ transplantation, the national co-ordinated organ retrieval programme and a national registry waiting list (78). It was a time which brought to the fore the conflict of interests surrounding public funds for the purchase of medical equipment and medical expertise from the private medical sector in competition with public health provided services (75, 76). (See Appendix 1.5 for a summary of the development of New Zealand dialysis services).

One key advantage that the renal service had was a development model, which promoted home dialysis as a national goal (69). Alongside the increasing numbers of patients admitted for Chronic Kidney Disease (CKD) was a strong emphasis of assisting patients to dialyse at home instead of the institution as a ‘free universal’ health care service nationwide. Renal physicians emphasised that an important reason that universal care is available is because there are no “financial
disincentives” (69) as in the United States, where dialysis centres operate for ‘profit’ or require the patient to be eligible for ‘medical insurance’ to be able to dialyse (79, 80).

In the last ten years, a number of key public health strategic policies have reinforced the movement towards the ‘home setting’ and more explicitly the ‘home’ as a place to be targeted.20 Home-based services is promoted as an ‘empowering’ process for ‘patient independence’ as well as a viable solution to rising costs of medical services and equipment.

A person with Chronic Kidney Disease (CKD) requires renal replacement therapy (RRT) in the form of either renal dialysis or kidney transplantation in order to maintain life, without which serious health complications and death is inevitable. Peritoneal dialysis21 is one of two main forms of RRT that is used in the home setting.22 It is the most utilised treatment mode for patients in the Central Region and across the country. The other is Haemodialysis.23

The provision of renal dialysis24 services in Wellington began in 1976 from the haemodialysis training unit in Owen Street, Newtown. After twenty years of operation, the unit relocated in October 1997 to a new $1.7 million building provided by the Wellington Regional Hospital at Riddiford St called the Margaret Stewart House.25 At Margaret Stewart House patients, receive an intensive haemodialysis (6 to 8 weeks) and peritoneal dialysis (2 weeks) training programme in the English language (81). Carers of peritoneal dialysis patients are also offered training so that they can assist at home. No equivalent educational programme is available for

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21 Peritoneal dialysis: treatment for kidney failure in which dialysis fluid is introduced into the peritoneal cavity to remove wastes and water from the blood. There are two types: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Automated Peritoneal Dialysis (APD), which can take up to 30 hours or more a week.
22 When I started interviewing participants in the study at November 2007 there were 83 peritoneal and 34 home haemodialysis patients. There were 60 peritoneal patients and 58 on home haemodialysis in 2006. Personal communication, estimates provided by the Wellington Renal Unit. Excludes numbers for Hawkes Bay area.
23 Haemodialysis: treatment for kidney failure in which the blood passes through an artificial dialyser to remove wastes and water which can take up at least 20 hours a week.
24 Renal dialysis is one form of renal replacement therapy for a person with chronic kidney disease. The other form is kidney transplantation. A person needs to have either one of these therapies to maintain life.
25 The new renal facility was named after a Wellingtonian woman, named Margaret Stewart, donor of the bequeathed funds for the new building left to the New Zealand Cancer Society. It provides an out-of-town residence for oncology patients for about 40 people.
carers of haemodialysis patients. If a patient does not have kidney organ transplantation or withdraws dialysis, they are supported by the renal unit to undergo palliative renal care until the end of life.

The state’s intended goal for a dialysis patient is the same goal for all patients who enter the public health system; he or she is encouraged to “lead an independent life” (6, 69, 72, 82-85). The dialysis unit fosters an approach where clinical staff (renal nurses and physicians) support and encourage patients to do aspects of the treatment regime on their own, while providing assistance only when required; a philosophy for the “empowerment of patients”. At the same time, dialysis patients are also expected to comply with ‘the doctors’ orders’ or the recommendations of their physicians.

1.5.2 Housing for dialysis patients

In the case of ‘home dialysis’ or home-based therapy, ‘housing’ is described as a “non-clinical” and “non-medical” aspect of patients’ everyday life, and fits into the same category as ‘transport’, ‘finance’ and ‘social supports’. This very ‘narrow’ definition of housing for home dialysis is somewhat surprising, given that the six New Zealand district health boards in the Central Region responsible for the provision of dialysis services have identified ‘home dialysis’ as a key target for development in response to the exponential rates of hypertension, cardio-vascular and diabetes amongst Pacific communities both currently and in the next two decades (86).

In New Zealand, when a patient is referred for home dialysis, the public hospital renal service carries out an inspection of the patient’s dwelling, sets up a delivery schedule of dialysis disposables and depending on the mode of dialysis installs relevant equipment, like a haemodialysis machine. In some cases the water fixtures and plumbing are modified, the costs of which are covered by the public health system. If the patient, for whatever reason decides to relocate and move out of the house, they are charged with the cost of having the machine reinstalled at a new address. The extent to which the cost of reinstallation when moving house is

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26 The state also accepts the costs of medical supplies, including the $1,800 the first installation of a haemodialysis machine. If the patient is a tenant of Housing New Zealand Corporation and City Council Authorities, the district health board negotiates with the respective organisations to have the plumbing renovations carried out and included in the cost.
seen as a disincentive for patients to relocate and resume home haemodialysis is not known, but has to be assumed to affect the rates of home dialysis.  

Home dialysis needs a substantial amount of storage space for medical supplies, as well as a continuous supply of clean water and electricity. Other requirements include the regular disposal of rubbish and waste, such as needles, packaging, sanitary bandages and plastic intravenous bags (for peritoneal dialysis). As will be shown in the results chapters, dialysis families can be embarrassed about the high volumes of household rubbish that accumulates from dialysis treatment.

Patients are expected to do tasks as part of the standard dialysis routine such as: setting up equipment, monitoring fluid and nutritional intake, needle insertion and maintaining a sterile treatment area. Additional hours and effort is also involved where the patient and their carer need to place telephone orders with hospital suppliers and regularly unpack large quantities of consumables that are delivered for treatment. If they need to, patients can call clinical staff, through the hospital ‘24-hours telephone help-line’ in the same way that patients at the public hospital or satellite unit can approach staff who are on duty (82).

1.5.3 The impact and benefits of home dialysis

The benefits of home dialysis are improved practical and social outcomes such as greater self-responsibility, maintaining employment, greater flexibility and better quality of life (69, 72, 80). However, it must be noted that appraisal for clinical effectiveness in most studies which compared home haemodialysis with hospital dialysis tended to have a selection bias with those patients who were healthiest and most able being selected for home haemodialysis (87).

Patients and their families can be faced with major physical complications, psychological stress and depression while undergoing dialysis (88). Those living with dialysis also have to cope with the on-going involvement and obligations with the state and often their families are involved in one or several capacities.

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27 The issue of relocating to a new address was particularly relevant for younger patients who were more transient than older patients and desired greater freedom for independence and separation from their families.
All patients today have a journey – many tortuous – and mostly the route taken is dictated by specialist/procedure/clinic availability i.e. the route has little to do with the patient and much to do with the service provider. Focusing on changing the patient’s journey stems from the traditional, acute disease management model (i.e. hospital based), which does things to patients, this minimises the ability to incorporate the patient within a partnership of care in order to arrive at a management plan that best suits the patient (p. 44) (89).

In spite of this, there appears to be little support offered to New Zealand patients to manage their depression (89). This is of concern, particularly since the effects of depression on patient survival are considered to be as significant as medical risk factors (90).

Overseas studies have reported similar concerns among patients and their carers from living with dialysis. Chinese families of patients experiencing dialysis in Hong Kong had day-to-day experiences of: decreased physical and emotional energy; the unavoidable emergence of socioeconomic problems; and the exacerbation of emotional reactions and stress (91). Similarly, carers shared the same financial, emotional, social and health-related problems experienced by the patients that they cared for (92).

Morton, Tong et al. identified 28 characteristics of dialysis important to patients (93). These were: (i) survival; (ii) convenience of dialysis at home; and (iii) dialysis-free days. Those which were most important to the dialysis carers, included: (i) convenience of dialysis at home; (ii) respite and (iii) the ability to travel.

There has been relatively little research done about the housing status of home dialysis patients in New Zealand (94). This might in part be explained because there are very few studies overall about dialysis patients’ “quality of life” and “satisfaction” (94, 95). Another reason is because the main information collected about dialysis patients through the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) does not include patients’ addresses, income or non-clinical matters in which housing might be included.28 When patients register for home dialysis, the renal unit assesses the suitability of their homes; however, I did not request or have

access to this information. I hope that the participant and key informant interviews will shed light the barriers that prevent Samoan dialysis patients taking up home dialysis.

1.6 Home Detention

1.6.1 The home for ‘co-operation’ and ‘honour’

In the 1980s at the start of the health sector’s decentralisation, the justice sector faced its own major structural and organisational downsizing. Borstals and corrective training centres, which had been well established across the country for nearly 70 years were closed and disestablished. Perhaps what is less known is that the rafts of new community-based sentences were ‘introduced’ and ‘expanded’ to improve justice outcomes for Māori and Pacific offenders. The judiciary of the 1980s recognised the “benefits offered by diverse cultural and ethnic groups” such as “Maatua Whangai, hapū, iwi…and religious groups” by the Crown’s obligation to Māori under the Treaty-o-Waitangi: “…the original intention [of CBS was] strengthening links for Māori and Pacific offenders to their family (Whanau) and tribal (Iwi) links, rather than placing them within institutional structures” (p.158) (96).

The placement of prisoners into the community and home setting is long established. Almost a century and a half ago when New Zealand innovatively instituted a national probation system under the 1886 Act, whereby, ‘Probation’ became a court sanctioned punishment premised on the notion that some offenders would be better placed ‘within the community’, with ‘restricted freedom’ and ‘formal supervision’, rather than being ‘locked’ inside the prison institution. As a practice adopted from colonial Westminster prisons, some New Zealand prisoners (especially those deemed naïve, or being discriminated against) should for their protection, be ‘separated’ from the negative influences of other prisoners within the prison institution (97).

The notions of ‘separation’, ‘segregation’, ‘punishment’ and ‘protection’ form part of the historical development of the early prison’s establishment of ‘community-based sentences’ (CBS). Underpinned by two important philosophical notions: ‘testing’

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29 Borstals and Corrective Training centres were run by wardens who instituted ‘short, sharp, shock’ military disciplinary programmes, until they were abolished in 1981 by the 1975 Criminal Justice Amendment Act (CJA).
(probation, Latin) and holding ‘to word of honour’ (parole d’honneur, French) (98); a detainee’s obligation while on probation is to behave well, and ‘honour’ the ‘limited’ freedom sanctioned to them by the courts, ‘without’ committing other acts of wrongdoing.

‘Community Services’ were significant because they required the “prior consents of individuals and organisations”; and for the first time, also the “prior consent of the offender” (p.26) (96). This ‘three-way’ co-operative triangle individuals/community organisations, offender and the state) was intended to reduce the institutionalisation of offenders (96). More importantly, ‘joint consent’ was a way to “formalise co-operation” between individuals, communities and the state. As seen in other international jurisdictions home detention by electronic monitoring was introduced as an important solution to New Zealand’s institutionalised prison services:

1. community-based sentences would reduce the use of incarceration and relieve prison overcrowding;
2. they were a more appropriate response to crimes of intermediate and lesser gravity;
3. the costs of corrections budgets would be reduced;
4. Community-based sentences would increase the interchange-ability of sanctions (p. 8) (96).  

Civil society (the community and the home) is therefore an important place for individuals to be ‘reformed’ and ‘rehabilitated’ alongside the mandated assistance and supervision of the state judiciary and law enforcement agencies. To summarise the history of home detention I have provided a time-line of events to chart the development of community-based sentences and home detention in the home setting (see Appendix 1.6).

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30 An amendment in 1980 to the Criminal Justice Act 1954 was passed, establishing the sentence of Community Service. It came into effect on 1 February 1981. The Act also expanded existing non-custodial sanctions namely: Probation, renamed Supervision and Periodic Detention.

31 Three community-based sentences, Community Service, Supervision and Community Programme were introduced as part of this regime. Community Service required the offender to complete a minimum of between 20 to 200 hours of voluntary unpaid work to a charitable organisation and had to be completed within 12 months Community Care.
As will be discussed later in Chapter 2, the health and correctional workforces were expected to respond more effectively to the wider and culturally diverse patient and prison populations both operationally and at the front-line. Home detention requires a person convicted of a serious crime to undergo their custodial sentence at their own private home or residence. If a person is sentenced for home detention without doing any 'jail time', it is because they pose a low risk to society and they have a low risk of reoffending. If on the other hand they are required to do incarcerated time inside a prison institution, then it is because of the high severity of their offence.

When released into home detention, the detainee is under the authority of the Community Probation Services (CPS), an arm of the Corrections Department. They are fitted (non-surgically) with surveillance equipment called the Personal Identification Device (PID) which emits an electronic signal to the HMU (Home Monitoring Unit) installed at their house. The PID also known as the ‘tag’, ‘bracelet’ or ‘anklet’ is worn continuously at all times for no longer, than 12 months in a sentence term and can cause discomfort and irritability (99). The signal transmitted by the PID is remotely connected over a long distance to the contracted private surveillance company (G4 or Chubbs New Zealand Ltd) who monitor the detainee’s location and whereabouts.\(^{32}\) If the signal is deliberately or accidentally tampered with, surveillance officers come to the detainee’s home to inspect the equipment and assess whether the detainee is adhering to their sentence. CPS can notify the New Zealand Police to have the detainee removed from their location and returned for breach of their sentence to state prison.\(^{33}\)

The provision of court sentencing services for women was set up in 1944 when the Womens’ Borstal was built in Tawa located about 15 km outside of Wellington. Following the formal closures of other borstals for prisoners around the country the 1970s, the facility was converted into a Youth Prison in 1981 and then expanded as the Arohata Womens’ Prison in 1987. Arohata provides accommodation for 154 female prisoners with minimum to medium-maximum security status and about 73 correctional staff are employed there (100).

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\(^{32}\) Department of Corrections, Community Probation Services Operations Manual: Introduction to Electronic Monitoring. Section 33(2) - (ii) and section 107K Parole Act 2002.

\(^{33}\) A home detainee needs to gain permission from Housing Corporation to stay in a state property for three months or more; similarly, a 'tenant' requires permission to sponsor a home detainee for three months or more.
Prisoners are offered a range of educational and rehabilitative programmes in New Zealand prisons that are funded and run by Corrections. However, the eligibility for these programmes is restricted mostly to prisoners who have completed two-thirds of their sentence and have been convicted for two years or more. Effectively, this policy, also known as the ‘66% Rule’ prevents all other imprisoned persons, including those on home detention from being eligible to attend structured programmes to help them address issues associated with their offending. Detainees can ask their probation officers to help them find relevant programmes out in the community when they are on home detention, or they can approach established non-government or private organisations directly.

1.6.2 Home as ‘approved premises’

A prisoner being considered as suitable for home detention is assessed by the Corrections Department for ‘criminogenic indicators’ by a computer-based statistical model called RoC*RoI; the Corrections Integrated Offender Management System (IOMS). IOMs use a range of predictive and diagnostic tools to assess the likelihood of reoffending, reconviction and reimprisonment. Factors such as an offender’s criminal history and demographics are used to assess the risk of re-offending based on: 1) an offender's probability of reconviction within the next five years; 2) the seriousness of the re-offending; and 3) the likelihood of imprisonment (101-104).

The legislation for all community-based sentences, including home detention does not incorporate the word “families” nor familial descriptions such as whanau, iwi, extended family, parent, grandparent, spouse, sibling and children. Individuals living in the same house as a detainee are recognised in statute as “relevant occupants”.

Under the Sentencing Amendment Act 2007, home detention is ranked as the ‘severest’ punishment of all community-based sentences and an offender was permitted to apply for home detention irrespective of the type of offence that was committed.

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34 A range of assessment tools are used to identify criminogenic indicators, the most important one is called RoC*RoI (Risk of Re-Conviction*Risk of Imprisonment). Factors such as an offender's criminal history and demographics are used to assess the risk of re-offending based on: 1) an offender's probability of reconviction within the next five years; 2) the seriousness of the re-offending; and 3) the likelihood of imprisonment.
The estimation of the success of home detention, as with other forms of punishments belongs to a complex notion in sentencing called ‘net-widening’, which occurs when: the widening control of the correctional system increases through the introduction of a new sanction (p. 75) (97). This emphasis on control, rather than outcomes, can lead to an increased use of alternatives to either lesser, or more restrictive sentences that might have been previously used by the judiciary. Overseas studies have questioned the efficacy of home detention in decreasing prison crowding and offending rates and were seen in the early years of home detention implementation. As Hylton has argued, the widespread use of intermediate sanctions (CBS) had created a range of undesirable effects on both the justice system and society in general, specifically because of the way that ‘state control’ has increasingly been extended over greater proportions of a population (105). In reviewing a range of evaluation programmes, he argued that the overall expenditures involved in running CBS approximated to “mini-institutions” and cost more to run than prisons.

Blomberg studied the uptake of home confinement in the State of Florida from 1980 to 1987 of over 100,000 offenders. Over the first four years of its operations, Florida became increasingly reliant on imprisonment for both drug and non-drug felony convictions; and home confinement enabled the state to supplement probation sanctions. As “front-end” strategies proliferated, it accelerated state social control by targeting individuals and/or families for earlier and earlier correctional intervention efforts (pg. 198). These policies had a negative impact on families through the increased involvement of agencies that work alongside criminal justice, such as mental health, welfare agencies and the larger political economy, evidence of the wider decentralisation movement in advanced industrial societies (106). The Florida programme produced what Blomberg highlighted as the “unintended consequences,” of home confinement: lack of adequate information and support provided to families. It also increased the potential for family domestic disputes; neighbour disputes; and new problems involving other family members (pg. 193).

35 In New Zealand prior to 2007 the courts could not directly sentence a person to home detention. A person who received a sentence of two years or less had to apply to the Parole Board at the beginning of their sentence for approval to be placed on home detention. This contrasts to a person who at the ‘back-end’ of their imprisonment sentence (of two years and more) applies for approval for home detention. The Sentencing Amendment Act 2007 allowed the courts to directly sanction a person to home detention. The two home detainees in my study were sentenced to ‘front end’ home detention.
One of the key issues here is the direct involvement of the criminal justice state, in the lives of people, who would not have otherwise been exposed. Home detention involves members of a detainee’s household who would not have been involved, if the detainee were institutionally imprisoned.

1.6.3 Housing for home detainees

There are several descriptions in the legislation about the detainee’s home: the “approved residential address”, the “area of probation”, “home detention residence” and most interestingly, the “curfew address of the Chief Executive of the Department of Corrections”. The prisoner’s home must have landline or cell phone coverage and be free of potential interferences that could affect the electronic surveillance equipment, such as transmitter sites, corrugated iron structures, satellite dishes, ham radio operators, electricity substations and the like (107).

An occupant who is living in the house and aged 16 and over has to give consent to allow the detainee to be housed for judicial imprisonment. An “occupant” can also be the “approved sponsor” who is the person solely responsible for the welfare and care of the detainee over the duration of imprisonment at home. A sponsor can be a family member, spouse, friend and flatmate.

Surveillance equipment can be approved for instalment outside of the home, at a place of employment or at an educational facility. This is an option, which on average is granted for about 10% of all home detainees because of the benefits for the wider community (108).

Two key outcomes for detainees on home detention are: the enforcement of “restricted freedom” and the “ease of transition back to the community” (103). The effective assessment of a person has to mitigate the risks of reoffending through proper placement and electronic monitoring at home. Programmes for rehabilitation, employment and compulsory services to the community are also factored into the detainee’s conditions to ensure that victims of crimes are protected, and that society is assured that justice has prevailed for the wrongdoing that was committed.
1.6.4 The advantages of home detention

The Department of Correction’s policies promotes amongst its key objectives: the reduction of “housing inequalities” by way of improving “interagency collaboration” (109) and “finding stable accommodation” (110). Overall, however, New Zealand prisoners’ can experience serious accommodation issues and often end up in housing debt, before and after incarceration. Some prisoners become anxious and fearful of letting go of their state or subsidised rentals, because they are afraid of not being able to attain another house when they leave prison. Others return home to find their belongings and property vandalised (31, 46, 111-116).

The inability to find a ‘suitable address’ is a significant reason why detainees, particularly Māori detainees fail to be approved for home detention. Risk and vulnerability often propel prisoners into constant emotional stress and financial housing debt that can lead to payment arrears and loss of property bond (31). Similarly, detainees can also experience on-going stressors associated with probationary obligations and the long-term monitoring conditions imposed by the state through Corrections (117, 118).

One of the most significant issues of home detention, signalled in the name, is the use of home, traditionally a place of privacy and security “as jail, prison or detention facility”. This leads to the blurring of boundaries between what is public and private (9, 105, 106, 119). Moreover, home detention is a court sentence that has to been seen in the wider context of the criminal justice system, but is generally not well understood by the general public.

Feminist discourses about the impact of state imprisonment in the home argue that home detention leads to the inversion of the formal roles of care normally provided by the State. This is seen particularly with respect to the central role that women tend to assume within families in which persons (mostly men), who are sentenced through the court system, become subordinated and taken care of by the family household (mostly women) (120).
Despite the long stated New Zealand policy intention that “imprisonment should be the last resort”, (97), it would appear in the literature, that a crucial juncture occurs wherever the modality of imprisonment becomes linked to vulnerable sectors of the community (119), so that the costs of care become transferred to individuals and groups with links to the offender. These are also likely to be the most vulnerable families, women and children (99, 119, 121, 122).

A criminal conviction can have an effect on the life of an individual in a deep and disruptive way, much the way that chronic illness can. Victims of spousal and intimate violence are constantly placed in positions of vulnerability and potential harm by detainees (spouse, boyfriend, husband, son) returning back home to resume and to complete their home detention sentences (123). “Sponsors” for male detainees, are most often those who have been subject to the violence of those they are trying to support on behalf of the state. This exposes and deprives them of financial security and resources (122, 124). On the other hand, the electronic monitoring of detainees sentenced to intensive supervision and undergoing drug rehabilitation programmes were shown to reduce recidivism rates (125, 126).

While the purpose of CBS is to reduce the reliance on the use of prisons or formal institutional settings, some studies have suggested that EM is no more effective in reducing offending rates than other prison diversion programmes set up for non-violent offenders or those convicted with drug possession, petty theft, welfare or housing fraud (127). Inconsistencies in the way that home detention is enforced has also been seen problematically because of the discretionary decisions of correctional officials using EM as a “case management device” rather than being applied on the basis of “crime-type and risk seriousness” (128). Young juvenile males in a study of a Californian diversion programme had in 51% of cases truly diverted from the greater penalties had the programs not existed. However, this was offset by 49% of cases where greater state interference was experienced because of being diverted into diversion programs (Blomberg 2004 cited in Hylton).

One of the interesting aspects of home detention that will be discussed in the next chapter, is the reliance that the state has on the New Zealand private security sector to undertake tasks which correctional and police enforcement officers used to do.
Similarly, in the public health system, private sector caregiver organisations are contracted for certain tasks that used to be carried out by public health nurses. In addition, this too highlights the shift of state to community-based and home-based services by professional and allied professional organisations. It was difficult to find any literature that showed where additional financial resources have expanded in the same way for families.

The legislation and policies of CBS has always promoted the altruistic values of “giving back to the community” and in some cases to the victim. Voluntary service could, and still can be, considered reparative for wrongdoing.\textsuperscript{36} If the offender directly interacted with community organisations, he or she would be influenced positively, which can have both rehabilitative and deterrent affects upon an offender’s future criminal involvement. A formal process that facilitates offenders and victims coming together to resolve issues associated to criminal offending that is supported by the New Zealand judiciary is called restorative justice.

Restorative justice gained statutory recognition with the passing of the Sentencing, Parole and Victims’ Rights Acts 2002, and the Corrections Act 2004. It gained formal usage for young offenders when Family Group Conferences were legislated for under the Children and Young Persons’ and Their Families’ Act 1989 and has operated in various judicial forums that encourage the obligations of offenders and the perspectives of victims. The most advanced form of Samoan restorative justice that has gained increasing recognition in the courts system is a Samoan traditional apology called the \textit{Ifoga}.\textsuperscript{37} The apology entails the offender (in some cases also a family member) to kneel before the victim while covered with a woven traditional fine mat. Kneeling with humility and remorse is the profoundest form of apology that a person can make to another person for severe acts of wrongdoing in Samoan society. Acceptance of the apology is shown by the removal of the fine mat from those kneeling; it is a symbolic and physical gesture of reconciliation and ‘forgiveness’. One of the important outcomes of an \textit{Ifoga} is that the apology circumvents any retaliatory acts such as revenge between the parties concerned.

\textsuperscript{36} Four community-based sentences under the Criminal Justice Act 1985 included: Periodic Detention (ss37-45), Community Service (ss29-36), Probation, renamed Supervision (ss46-52) and Community Programme (ss53-57). Community service (ss29-36) by consent of the offender permits for the first time a sentence of 20 to 200 hours could be supervised by another organisation other than corrections.

\textsuperscript{37} I could not ascertain any official figures about \textit{Ifoga} as a restorative justice process as part of judicial proceedings.
Also described as “dispute healing”, the ifoga in judicial settings is seldom used, however, like other forms of dispute resolution it can increase understanding between aggrieved parties and generate “reintegrative shaming”, which generates disapproval of the person (offender) within a continuum of respect\(^\text{38}\) (129).

In the home detention study that I conducted, ifoga was discussed as an important formal process that brings together offenders and victims to resolve issues associated to offending based on the Samoan notions of forgiveness and wrongdoing. For two of the participants, ifoga had a profound effect on how the detainee and the family managed the complex issues of shame and reintegration during home detention. This is discussed in detail in the results Chapter 7.

Despite the potential benefits and advantages of home detention, opponents of this sentence advocate that there are risks of releasing offenders of serious crimes into the community, especially for the victims of intimate violence (123, 124). As will be shown later, key informants of the home, detention study discussed this as a serious problem for some female home detainees where domestic violence, predominantly from spouses, had continued over the duration of corrections supervision.

1.7 Gaps in the literature that this thesis intends to fill

There is a paucity of information in the literature about families in receipt of formal home-based services such as home dialysis and home detention and how they respond to the formal obligations required of them. There is even less information about the homes and built environments that are used for these services and the way in which they might inhibit or permit families to carry out the formal obligations expected of them. There is some literature about the way Samoan families in Aotearoa/New Zealand conceptualise and understand their physical and sociological environments, but virtually nothing in relation to home dialysis and home detention. The way in which Samoan families interpret and understand their home environments within Samoan cultural frameworks is also a major gap in the literature that this study intends to generate insights and knowledge.

\(^{38}\) Cited in Tuala, based on the work of John Braithwaite.
1.8 Structure of this thesis

This thesis is organised into seven chapters. The Introduction, sets out the key questions of the thesis and introduces some of the history and background of how home dialysis and home detention services have become two important home-based services in Aotearoa/New Zealand as part of the decentralisation of public services of the 1970s and 1990s. This decentralisation coincided with state promoting policies and legislation that expanded home dialysis and imprisonment services into the family home.

Chapter Two provides a population-based description of the prevalence of chronic kidney disease (CKD) and prison incarceration in this country. The prevalence of CKD is very high for Pacific peoples; however, the uptake of dialysis treatment in one’s own home (home dialysis), compared to Māori and other ethnicities, is proportionately lower. Pacific people also have a low uptake of kidney organ transplantation and it is also unclear why this is the case. Presented here are the comparative costs between institutional and home-based dialysis and community-based sentences. Because of their relatively inexpensive costs, both these services are likely to continue as permanent services within the homes of Pacific peoples and all New Zealanders.

Chapter Three is a discussion about Samoan epistemological and cultural knowledge. It provides a framework for helping to understand Samoan society and its familial social obligations. The notion of ‘service’ tautua is part of a somewhat stratified social and political structure, which is embedded, in the Samoan traditional village and architectural landscape. This chapter describes how Samoan dwellings, fale Samoa influence the geographical and spatial underpinnings of familial social roles within the home. These cultural understandings still influence the way in which Samoan families living in New Zealand organise their day-to-day activities and their indoor and outdoor living environments. Associated with this is a sophisticated metaphorical framework based on Samoan ocean tides and winds which provides a unique way of understanding of the socio-political dynamics within Samoan contemporary society.
Chapter Four Research Method, reviews several examples of the participatory photographic method called Photovoice and its wide application for health research. In this chapter, I describe the steps that were taken to collect research data for this thesis using a multiple-case approach for Samoan families who underwent home detention and home dialysis in the Wellington area. Decisions around the investigation and recruitment of participants for each case study is also described with some of the challenges involved with the design and translation of the information that was distributed to the participants. For the study, I also designed a visual diary both as an aid for explaining the purpose of the research and as a guide about the photographic images that participants could produce with their disposable cameras. Consent forms, information sheets and formal ethical approval documentation are provided in the appendices.

Chapter Five is the results chapter for the Home Dialysis Study and presents the perspectives of 12 participants who have generously shared their experiences about the demands of dialysis treatment, at home and at hospital. A summary of the themes, which emerged from the participants stories and photographs, have been summarised in a table at the beginning of the chapter. An important focus of the study is the participants’ visual representations of how their houses are important places for healing and preparing for the end-of-life.

Chapter Six presents the results for the Home Detention Study, which presents the perspectives of three participants who kindly shared their stories about their experiences of institutional imprisonment, and home detention. This chapter also includes key informant interviews with prison officials. While only a small participant sample of two home detainees and one sponsor, the richness of the stories and photographs that were produced for the study raises several important issues about the home as an environment for incarceration. A summary of the themes at the beginning of the chapter will also help to highlight several unique insights about Samoan communities and the Samoan cultural practices associated with restorative justice known as Ifoga (apology).

Chapter Seven Discussion presents the findings from both case studies and the conclusions I draw from them. I consider some of the positive aspects of home-
based services and some of the major gaps where the state is failing to assist families. In my conclusion, while generally I form a positive view that Samoan families in receipt of home-based services have experienced improved levels of independence. The uptake of home dialysis and home detention are diminished by factors associated to the quality of the houses, which Pacific families occupy, and how these can greatly influence the effectiveness and levels of wellbeing experienced by those living with the formal obligations of home dialysis and home detention.
2 PREVALENCE OF HOME DIALYSIS AND HOME DETENTION

In this chapter, I discuss the prevalence of home dialysis and increased rates amongst elderly and diabetic sections of the Pacific population with co-morbid diseases affected by end stage renal disease (ESRD). Highlighted is Pacific peoples’ low uptake of home dialysis and higher use of institutionally based treatment. I then compare the costs of institutional and home treatment settings, as well as the costs of kidney organ transplantation, of which Pacific people’s uptake rates are also significantly low. Thirdly, I discuss briefly, the dialysis workforce, which has over the years needed to expand to meet the growth and establishment of dialysis units across the country.

In the second half of the chapter, I consider the numbers of Pacific prisoners convicted through the court system, the costs of home detention versus institutional imprisonment and the New Zealand correctional workforce. Pacific prisoners when applying for home detention have higher rates of approval when compared to Maori, but for both ethnic populations, the prevalence of serious violent offending and high rates of police apprehensions are factors that keep the state entangled in the lives of Pacific families.

2.1 The low uptake of Pacific patients for home dialysis

One of the areas of investigation for my study was to find out from dialysis patients and their families factors that assist or hinder their ability to dialyse at home. When a patient agrees to carry out dialysis at home, they are given training to be able to dialyse at home independently, without the need for medical assistance. Both New Zealand and Australia have dedicated training programmes to encourage patient uptake of home dialysis and a workforce experienced to support them (69). While the method of training patients was not a specific area for investigation in my study, it has to be acknowledged that this could influence patients’ and families’ decisions around taking up home dialysis (95, 130).
The medical treatment of chronic kidney disease (CKD) is a specialist area and one of the primary concerns raised frequently by renal physicians is the “epidemic” increase of elderly patients with CKD and comorbid conditions (80, 83, 130-136).

Many elderly patients, particularly male, are amongst those who often refuse to dialyse at home. Māori and Pacific rates of end stage renal disease are similar, although, there is a marked incline for Pacific aged mid-40s to mid-60s as illustrated in Figure 2.1. Comments from renal unit staff I talked with have found it difficult to understand why this is the case and hoped that my study would help to uncover some of the reasons behind it (82, 137).

![Figure 2-1 End Stage Renal Disease ANZDATA Registry Annual Report 2010](image)

In Aotearoa/New Zealand, the most prevalent mode of dialysis used at home is peritoneal dialysis. Figure 2.2 (below) shows that Māori had a higher rate of home peritoneal dialysis than Pacific, although this difference has decreased (138).
Figure 2.3 shows there are higher rates of Pacific commencing in-hospital haemodialysis compared to Māori.

Pacific patients' rates of new admissions for dialysis have attracted considerable concern from district health boards (84, 89, 131, 133). The prevalence of CKD in New Zealand is greatly affected by the rate of diabetes, which are extremely high for...
both Pacific and Māori. At least 40% of all new patients have Type II diabetes, which has a multiplier effect with comorbidities in premature mortality (89).

In a study carried out across eight regional centres that provided renal services in urban areas in 1992 to 2001, diabetes accounted for renal failure in 73.7% of Māori and 64.6% of Pacific Island people (139). However, Pacific people have the lowest prevalence of kidney transplantation in the country (138). New Zealand studies have shown that higher numbers of elderly patients, regardless of ethnicity, who have greater co-morbid diseases receiving RRT (particularly vascular disease and diabetes) have less chance of being accepted onto the waiting list for a deceased donor or living donor transplant (139).

A report that was compiled about Māori and Pacific people's low uptake of kidney organ transplantation highlighted the importance for transplant units to demonstrate adequate communication skills and cultural competence when working with Māori and Pacific in order to dispel inaccuracies about transplantation (140). Fig. 2.4 shows Maori and Pacific rates over a four-year period to be consistently low.

In the United States, despite wide variations in primary cause of ESRD, clinical characteristics, age, comorbidities and body size at dialysis initiation, Asians and
Pacific Islanders within the Trans Pacific Renal Network\(^{39}\) between 1995 and 2002, experienced better survival after transplantation but substantially lower transplantation rates compared with Caucasian patients (from a cohort of 24,963 dialysis patients) (141).

Unless Pacific rates for transplantation and home dialysis improve, the costs associated with hospital dialysis treatment overall are likely to continue and grow. This growth is compounded by the projected rate for RRT in the 15-69 year age group between 2005 and 2015, which is expected to grow by 57% (89).

### 2.1.1 Costs of home dialysis, institutional dialysis and kidney transplantation

The economic cost-effectiveness and social value attached to a patient who dialyses at home make it a highly preferred treatment option, from the view of physicians and health administrators (69, 80, 83, 89, 131, 142).

On average, there is a 30 to 50% cost difference of all types of home dialysis modalities, because of the absence of capital and labour outlay associated with in-unit hospital dialysis services (89). Between 2003-2004 Manukau DHB estimated that the annual costs for a patient to dialyse at a hospital in-centre were: $64,318 per annum compared to a satellite centre ($48,172). If a person carried out his or her own treatment at home using a haemodialysis machine ($33,585) or by home peritoneal dialysis ($36,614), the cost difference was significant (89). An important point to make here and which will be highlighted later in the results chapters of the participants’ stories is that other care related costs at home such as electricity, water rates, electrical appliances and waste disposal are not factored into the overall costs for home dialysis.

The costs of a kidney organ transplantation operation (including pharmaceutical costs and hospital stays) range from $105,000 to $130,000 (based on 2003 figures).

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\(^{39}\) TPRN (Trans Pacific Renal Network) collects ESRD data of Hawai‘i’s five largest ethnic groups: Japanese, Native Hawaiian, Filipino, Chinese, and Caucasian. The Native Hawaiian population includes combinations of Samoan and other Pacific ethnicities. Asians and Pacific Islanders were much less likely to undergo kidney transplantation Samoan (0.62 [0.48 to 0.82], and Native Hawaiian (0.84 [0.72 to 0.96]).
It has been estimated to be the most cost-effective treatment as recovery of costs is $85,000 in the first year and $10,000 in each subsequent year (89).

2.1.2 Dialysis workforce

With higher survival rates of an aging population and an increasing rate of six percent per annum requiring dialysis; attention has been drawn to the capacity of the public health system to provide enough nephrologists and renal nurses in New Zealand to cope with the demands of renal replacement therapies (69, 83, 89, 138, 143).

In one of the first comprehensive studies that investigated the New Zealand dialysis workforce, a comparison of hospital/satellite and home dialysis showed that for every nine percent increase in patients using home dialysis, the patient/nurse ratio significantly decreases in the hospital/satellite setting (143).

As Bennett and colleagues have argued, coverage in New Zealand dialysis units, are adequately managed by overtime and callbacks, a management practice, which was made possible due to the high number of part-time staff employed. At 2009, there were 399 clinical staff (renal professionals, registered and enrolled nurses) working in 25 dialysis clinics. The patient nurse ratio in New Zealand is 1:6.3 compared to Australia 1:4.2, which had a much larger renal workforce of 2,916 staff that covered 228 dialysis units.

I could find no information about the renal workforce ethnicity within dialysis units, although from participants and key informants reports, there are very few Pacific nurses employed in the renal units and no Pacific renal physicians. While the number of renal units and staff around the country has grown, I was unable to explore in any detail whether the management approach that utilises a high ratio of part-time nurse employees gives rise to issues of equity; and more importantly how this would impact on patient service satisfaction. This could be an area for further exploration, particularly with respect to nurse employee work satisfaction.
2.1.3 Summary

The high rate of CKD that necessitates the need for dialysis treatment amongst Pacific is seen largely in the older age group of 50s, 60s and early 70s. Pacific have low uptake of home dialysis and are more likely to have haemodialysis in renal units, a trend that is compounded by the low uptake of transplantation. These two key factors highlight the significant on-going costs for Pacific utilisation of institutional renal services.

One of the important issues has to do with Samoan families’ decision-making around dialysis and transplantation. This raises the question about the disincentives for Pacific not selecting home treatment, when conceivably it could increase greater personal independence and would decrease the service costs associated with hospital care. If there are disincentives for families’ not selecting kidney organ transplantation, then what other alternatives are there to the long gruelling routine associated with regular dialysis treatment?

2.2 The prevalence of home detention

Community-based sentences (CBS) include: a sentence of imprisonment on home detention, intensive supervision, community detention, community work and supervision. CBS impose restrictions on a person’s time, mobility and approved attendances at specified rehabilitation and employment programmes. Home detention has an immediate focus on the home as a way of ‘containing’ and ‘securing’ a person for imprisonment while emphasising its punitive adherence to a range of “residential restrictions” such as “curfew” and “surveillance electronic monitoring” equipment (9, 10, 119, 144). While undergoing sentence, a detainee is “A person under control or supervision” of the state and agents employed by the state (Corrections New Zealand) subject to the 2007 Sentencing Amendment Act.
Figure 2.5 highlights the range of community sentences in order of hierarchy of severance, home detention being the most severe because it is a punishment of imprisonment. Community orders (grey scale) are mostly carried out concurrently or at the end of an episode of Community Sentences.

Pacific makes up 11% of the prison population and nine percent of the community offender population and is overrepresented in two areas of criminal justice: youth and serious violent offending. Pacific youth apprehensions (property and burglary crimes) were six to nine percent of all apprehensions from 1995 to 2006 (145). Pacific exceeded New Zealand European and other ethnicities for the 14 to 16 age group. This is of real concern given that these figures are standardised for the national Pacific population.

Before October 2007, home detention was a sentence in combination with a short-term imprisonment at ‘front end’ (for sentences of two years and less) or ‘back end’ (sentences of more than two years). After legislation changes in October 2007, detainees could be sent home, without serving any institutional time in prison. Those who were sent to prison (like the two detainees of my home detention study) had to serve at least 8 weeks because they were convicted of serious violent offences. The biggest proportion (76%) released for home detention after serving institutional imprisonment were Māori (55.4%), compared to Europeans (35.2%) and Pacific peoples (7.4%). Home detainees who did not serve prison time (24% of all home
detainees) were those convicted mostly of dangerous acts, traffic offences (26.4%) and property and environmental offences (25.2%).

Overall Pacific (mostly of Samoan ethnicity) make approximately 8.8% of all those who received home detention, with the largest number being European (45.4%) and Māori (43.0%) (146). In 2009, there were 231 Pacific home detainees and 312 in 2010. The next largest Pacific group convicted within the prison system was Cook Islands, followed by Tongan.

Women are more likely to do home detention (21.4%) than males or females sentenced to short-term imprisonment and home detention (10%), particularly those aged 20 to 29. Those aged 40 and over were more likely to serve home detention than prison.

While some home detainees committed serious violent offences during their term on home detention (4.4% from 2007 to 2011), the reoffending rate is comparatively low (2.1% in 2010), particularly when compared to those who reoffend on non-custodial sentences. Pacific offenders overall have low reoffending rates although it was difficult to find exact estimates for this. For institutional imprisonment, Pacific detainees are also less likely than Māori or European to be involved in prison incidents such as assaults, illicit drug use, self-harm and attempted escapes (110).

2.2.1 Suitable accommodation

The prospect of home detention might appear far more attractive than institutional jail time; however, the attainment of ‘suitable’ accommodation can be very difficult for many prisoners as evidenced in a cohort study of 7,606 offenders. The criteria of approval involve various factors such as appropriate sponsor, location and conditions of sentencing. A significant number of Māori prisoners (2,851) who were granted leave to apply for ‘front end’ home detention to the Parole Board, did not to apply to the second stage for final approval, because they were unable to secure a “suitable home address” (p.11) (147).  

In other words, out of 4,023 prisoners (all

40 At the first stage process the offender is required judicial permission at pre-sentencing to be able to apply for home detention in the first instance. If they are denied leave to apply, the offender could reapply from while in prison for home detention to gain permission from the New Zealand Prison Parole Board. Under the Sentencing regime of the Criminal Justice Act 1985, all offenders were required to apply for parole and release conditions as part of their sentence to a District Parole Board. The
For Pacific prisoners (female and male), the outcome of successful applications was better than Māori with 230/615 (or 37.4% of the total sample) at the first stage, and at the second stage 102/171 (60% vs. 52% or 289 for Māori). The Pacific approval rate was more comparable to approval rates for New Zealand European (61% male, 87% female), an aspect of the study the researchers could not explain (147).

The rejection of applications at the second stage of approval has relevance for the purposes of my study because the majority of prisoners (particularly Māori) are unable to provide a ‘suitable address’ (147). It signals the ‘disconnect’ between what the criminal justice system would like to achieve by placing more detainees into the home setting through community-based sentences and the shortage of ‘suitable’ places, where they could live for the purposes of imprisonment.

The above study also showed that 20% of Pacific prisoners did not apply for second-stage approval, but it could not explain why this was the case. One suggestion, following the Māori data, could be that some Pacific prisoners may not have had ‘suitable home addresses’, although, estimates for this are also unknown.

Female detainees generally experience major resettlement difficulties when they leave prison and often find themselves having to relocate with their children from place to place (148). A study in Christchurch about the “invisible children” showed that children of prisoners were often sent to live with extended families, and very often with grandparents (111).

Undertaking further research about Pacific home detainees can help to build a more comprehensive picture about the kinds of housing experiences that really exist. A

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Sentencing Act 2002 repealed many sections of the CJA 1985, and replaced the …. (number) District Parole Boards with the National Parole Board.
key objective of my qualitative study and using a photographic methodology is to investigate the housing experiences of this unknown population.

2.2.2 Costs of home detention and private corporations

The cost of home detention, since its introduction to New Zealand has not only expanded in use, but also through economies of scale become less expensive. Minimum-security prison for 12 months in 2007 cost the state $90,746 (including depreciation). In comparison, the average annual cost of a detainee who was imprisoned at home was $25,000 in 2008 (149) and even less in 2009 at $18,000 (146). Estimates in 2011 were $58 per day on home detention compared to $249 per day for institutional imprisonment.

The expansion of community-based sentences involves the substantive outsourcing of state funds for high-level security and surveillance monitoring of prisoners in this country. In the same way that the devolution of the public health services occurred, the New Zealand Police and the Department of Corrections law enforcement services went through a major shift, when it stopped providing a range of functional operations as it had always done. Corrections staff seemed unable to make the switch required to liaise with community organisations and individuals, rather than direct individual client work (pg. 158) (96). Consequently, the low referrals by correctional staff led to the low numbers of offenders being placed into the care of the community (96). Newbold also commented that despite government spending $5.86 million on Māori programmes (institutional training and marketing)42 the results that were anticipated from CBS did not meet the hoped for promise of reducing disparities for Māori offenders (98).

When Corrections contracted out services to the private sector company Chubb NZ in 1997 to implement and monitor electronic monitoring devices for home detention and community-based sentences, it underwent the same “three phases” trajectory as other jurisdictions such as the United States (9, 10), the United Kingdom (112) and Australia (150).
Bradley and Sedgwick have charted the New Zealand government’s massive transition away from its previous role as the “monopoly provider of policing services”. This has largely been facilitated by the fragmented private investigative and security guard industry sectors which developed massively from the “minimalist strategic regulation” since the 1970s (151). Functions like ‘monitoring’ and the ‘transportation of prisoners’ that was formerly carried out by New Zealand Police and Correctional officers was contracted out to private sector surveillance companies such as Chubbs NZ and G4S. At 2008 transportation alone was $12 million of Corrections vote budget, a substantial chunk out of an operation of over $1.9 billion in physical assets (prison buildings, reporting centres, etc.).

The private sector involvement of monitoring offenders covers a pool of 35,000 offenders on community-based sentences and orders, and approximately 8,000 on custodial sentences, which include home detention (149). As pointed out by Bradley and Sedgwick, this aspect of the nation’s security and safety is being excluded from public consultation: “[the] expanding role of private security in particular has not been the subject of either media or political debate or academic public sector or industry research” (p.469) (151).

As was the case for home dialysis, the costs of care for a detainee on home detention do not take into account other additional costs such as electricity, telephone bills and living expenses. If sponsors have to take time off work to be at home to support a home detainee, the state does not include these costs as part of the overall expenditure of home detention.

2.2.3 Corrections workforce

Despite the policing functions carried out by private companies, the Ministry of Justice is the second largest state employer, with approximately 7,000 employees on pay roll, including 3,310 corrections and 900 probation officers in 2008 (149). Of this number, Māori made up 22% and Pacific 9% of the workforce; both figures being disproportionately lower than the matching ethnic offender prison population held in custody and on remand, which sat at over 50% (Māori) and 11% (Pacific) respectively.
2.2.4 Summary

Pacific offending rates are disproportionately higher than the proportion of Pacific people in the general population and to a lesser extent comparable to Māori rates of offending. While Pacific people have higher approval rates for home detention, a noticeable reason for the low approval rates for Māori has to do with being unable to confirm a suitable address. The numbers of Pacific detainees unable to find suitable accommodation as part of their custodial sentence are unknown.

Home detention costs significantly less for the state to implement than institutional imprisonment and the State outsources a significant function of the surveillance and electronic monitoring of detainees to private contractors. I could find no information that incorporated the costs that families shouldered in the care of detainees at home.

In conclusion, this chapter has compared the costs of home-based and institutional services for home dialysis and home imprisonment. The State employs a sizeable workforce for institutional dialysis and prison services; however, more funds in comparison are used to fund private contractors to monitor detainees on home imprisonment than pay public health practitioners to assist dialysis patients at home. No sources were found that made mention of the costs, which affect private households, involved in the care of those on home dialysis and home detention.

In the next chapter, I present my epistemological approach, which provides an important framework for understanding the Samoan traditional and cultural concepts in relation to housing. This chapter will also contextualise the formal roles and responsibilities related to the care of the chronically unwell and imprisoned in Samoan society. It highlights the intrinsic values that help Samoan families adhere both directly and indirectly to the State’s home-based public services.
3 EPISTEMOLOGY

3.1 Section A - Samoan Epistemologies of Dwellings

This chapter considers four aspects of my epistemological framework: the house; the role of carers; the culture of tides and winds; and capturing of images. These epistemologies are grounded in a deep understanding of Samoan traditional cultural concepts. The indoor environment affects the use of space for health and this is a key focus of my doctoral study. However, this can really only be better understood within the context of how space is defined within a traditional Samoan house and how social roles, responsibilities and obligations are determined at three main regions of the house – the front, middle and back of house. As will be shown later in the results chapters, the range of formal and informal activities carried out in different areas of the house are thus pre-determined and influence even Samoan families living in Aotearoa.

3.1.1 Family dwellings in a village setting

Buildings within Samoan villages are strategically laid out in descent groups or stratified hierarchal clusters. The point of collection at the front of house is normally marked by an open space or field known as the malae (field), and provides the site for the largest dwelling called the fale tele ‘main house’. The ancestral site where the fale tele is located is often named after the first progenitor (leo’o) (152).

Samoan traditional dwellings are demarcated into two distinct geographical domains:

- front of house lumā fale, the ‘public’ domain of ‘formal’ activities such as the hosting of formal ceremonies and village meetings;\(^{43}\)
- back of house tuā fale, is the domain of ‘private’ and ‘informal’ activities. Included here are the household activities oriented around manual work and domestic duties like cooking, cleaning, planting and harvesting. At the back of house, descent groups sleep and live in their designated houses; the care, nurturance and welfare of family members are carried out. (See Figure 3.1).

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\(^{43}\) Ceremonial activities and events such as the alofisā ‘ritual distribution of kava’, fa’aaloaloga ‘oratory and ceremonial presentations’.
Samoan cultural wealth, which includes ritual household objects, practices and traditions, is integrated into the formal and informal processes of everyday life and is linked directly to what I have described as the “middle of the house”. Within the main ancestral house, the middle of the house (discussed in detail later) can denote the central area of the building, where important ritual household objects can be stored. A key area of interest of my study is to examine the Samoan metaphors, symbols and traditions embedded in participants’ experiences of home dialysis and home detention. As will be shown later in the results, participants discuss a range of Samoan culture and traditions in their photographs and interviews, and the relevance these have to their experiences of the built environment.

Experiences of illness are mostly associated with the back of house, because they involve messy tasks of care, but illness can also be linked to the middle of house in relation to Samoan traditional healing. Death is also associated with the back of house, as the grieving family prepare food in receipt of visitors. In the middle of house Samoan cultural wealth such as le toga fine mats become important as
objects exchanged during formalities. Incarceration is associated with the back of house through the obligation to protect, and related to warfare, fighting, and loss of blood, as well as the maintenance and preservation of political authority and social control (discussed later). At the middle of house objects of weaponry and warfare such as Tupua Taliva’a or war clubs and spears used by ancient ancestral figures, signify the importance of resolving wrongdoing and creating appropriate processes for forgiveness and healing.

3.1.2 Front of house/fale tele – ancestral house and Samoan Geom mentality

There are two architectural structures, which distinguish the fale tele as the dominant structure amongst the family dwellings. The first is the falelapotopoto ‘house gathering’, a spherical design, much like an “inverted taro plant” sent from the heavens by Tagaloa (152). The other is the afolau44, an elongated building (Photo 1) and believed to resemble “a boat (canoe) turned upside down” (152). Its architectural style is argued to have been imported from Tonga and modified for the Samoan environment (154). The canoe and taro motifs of the faletelae are replicated in the main mast (or stem) of the supporting interior centre posts (poutū), which can number from one to three posts.45

44 afo: fishing line; afolau: voyage
The architectural philosophical designs of the *fale tele* are believed to be linked to the families of the original building guilds of *Sa Tagaloa*, the first original master builders/carpenters *fau fale* (155). The constructed posts, open level floor, high domed roof, central supporting columns, permanent interiorised shelving, protruding struts and moveable woven blinds were named by master builders (156). According to *Sunia* (157), there are five ancient archetypal buildings from which all *fale tele* are modelled (See Appendix 3.1.2). The architectural features of these buildings form many of the Samoan linguistic references and metaphors used in Samoan oratory and traditions. For example, an orator’s welcoming speech might be used to emulate the beauty or auspiciousness of an occasion or event by referring to the distinctive architectural features of a building archetype: “*O le nei aso....o pei o le fale nai Amoa, na lau i ula ae pou i Toa*”. Translated: “*Today is.... just like the house of Amoa, thatched in red feathers and posts of Toa*”.

In all traditional houses, seating is arranged hierarchically and occupied by *Tulafale* (Orators) at the elongated posts (*pou lalo*) and by *Tamali’i* (Chiefs) at the two rounded areas of the building called the *matua tala*.

Samoan social identity is closely linked to traditional Samoan ‘gifting’ processes underpinned by indigenous social contractual ideas derived from the concept of *taualofoa*: “*e alofa atu, aua e sa e alofa mai*”, ‘reciprocation of love offered (by my family) because of the love offered (by your family)’ (158). Social obligations are also commensurate with the values of love, compassion, mutual respect and humility “*fa’afetaui le alofa ma le fa’aaloalo*” (152). Despite the introduction of Western paradigms through modern medicine, Christianity and commercialised economies; traditional dwellings have preserved the indigenous Samoan Geomentality (159). These notions become reinforced and upheld when families face one another in the formal and informal settings during every-day life events which cross the spectrum of human development: birth, illness, recreation, education, marriage, separation, imprisonment, death, isolation, distress and natural disasters. Individuals carry out their obligations within families and also with those outside namely, the state and

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46 Interestingly, Fuimaono Fereti identifies nine main Samoan architectural families. The list appears to be taken from *Te Rangi Hiroa* (1930) in a publication on Samoan house building. The families include: Aiga Sa Sao (Manu’a); Aiga Sa Lemalama (Tutuila); Aiga Sa To (Tutuila); Aiga Sa Leifi (Upolu, Atua); Aiga Sa Moe (Upolu, Aana); Aiga Sa Logo (Upolu); Aiga Solofuti (Savaii); Aiga Sa Sigi (Savaii); Aiga Sa Tagavailega (Savaii).
civil societies, obligations which are expressed and formalised at the front of house. (See also Appendix 3.2A and 3.4F).

3.1.3 Light and dark in the traditional built environment

The most notable feature of the *fale tele* is the openness of the building interior to the surrounding outdoor environment that makes it also visible from the outside. The inside merges effortlessly to the outside because there are no walls, except posts and the minimalist, non-furnished spacious floor is turned into a multifunctional platform for ‘front of house’ ceremonial protocols and the exchange of cultural wealth such as kava ceremonies, formal apologies, funerals, title bestowals and other significant life events and celebrations. Sound, light and wind converge seamlessly to replicate the dwelling places of cosmological figures in Samoan mythology and traditional lore. (See Appendix 3.2Ba)

Like other ordinary dwellings, light, sun, heat, wind and cold can be shut out by drawing down *pola ‘blinds’* of the circular enclosure. In Samoa *pola* are also drawn down when a person is sick to create private space. By drawing down all the *pola* of a traditional dwelling, a dark inner circular structure is formed and if a single *pola* is left open, a doorway or window creates the entrance or exit of an *aitu* (supernatural presence or being), thus, the space becomes like an inner sanctum (24). Because of this, Samoans normally avoid drawing down *pola* at any time to avert the creation of a dark oval space and thus avoiding the invocation or presence of spiritual and supernatural phenomena. Some Samoan villages still observe such secret rituals of this nature authorised only by certain chiefs (24, 160).

In the same way, mirrors and refracted reflections of fresh water spring pools are places where the presence of the supernatural can appear. Within this context, human experience can have many different associations that draw on Samoan cultural notions of sacred and profane; thus generating a range of different ways of understanding which Samoans view as the ‘seen and unseen’, ‘open and closed’, the ‘dark and light’.

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47 *Pola* are woven from *lau niu* and attached with pull-ties so that they can be raised or lowered.
48 The ceremony referred to here is conducted in the village of Faleasí’u. The ceremony can only be initiated on a specific occasion and only by certain families.
3.1.4 Life and death

Fale tele are synonymous with caves ana and forests; the restricted abodes of spirits which represent inviolate spaces for the maintenance of social cohesion, restoration and wellbeing. Houses offer refuge in the case for example of an elopement from another village\(^49\) or a serious incident requiring deliberation. When Samoans die, their homes are treated symbolically and physically as ethereal sites connected to the ancestral family house; a holding platform between this world (living) and the next (dead). The death of a Chief (tu’u malo), termed as Lagi ‘sky or heaven’, involves a formal commemoration within the village setting, where chiefs and members of the village gather to farewell him or her on their journey to the Samoan cosmological heavens from whence all Samoan families are socially and politically stratified. The ancient practice of placing the skeletal bones of high ranked individuals in the high rafters of the house\(^50\) preserves the memory of the ancestor and turns the house into a living shrine and ‘heaven’ for the dead and the living.

The ‘centre posts’ poutu of the faletele, are normally built from the hardwood of the ulu (breadfruit tree). Certain mythological stories show that the central posts represent the sister archetype (Po, or feminine principles) and the female progenitor (Tamāsā, ancestress). As the centre post ‘she’ can sanction life (pou ola), a role that is further signified by the prominent place that fine mats have within the inner structure where they are stored in the upper shelving or as some believe hidden beneath the earth\(^51\)\(^52\).

In pre-contact times a magālafu or ta‘āfi ‘fire hearth’ was lit at the ‘centre of the house’, near the centre posts and kept burning throughout the day and night to honour the indigenous gods of ancient Samoa\(^53\). It was used to invoke Samoan indigenous spirituality a complex religious knowledge associated to Va Tapuia.

\(^49\) Thanks to Richard Moyle for this comment.
\(^50\) Cultural Advisors agree that the bundle visible in the rafters in Photo 4.1 in Chapter 4 could be human bones.
\(^51\) Alo, in reaching the House of Po ma Ao, is instructed to weave his way towards his sister (centre pole, named Po), who would clear away the deadly path of spears jutting from all directions.
\(^52\) Pipimaleeleelele, an important fine mat of Samoa, was retrieved by Tualafalafa at the house called Matagilemoe, from her grandmother at the centre of the house, who was buried underneath the earth, and only her top half was visible above the ground. Refer, Tu’u’u, pg 25.
where family evening prayers (fanaafi fa’amalama, tapuaiga o Samoa) were observed around the fire (160). Since the wide conversion of Christianity in the late 1900s the hearth gradually became excluded from Samoan building design (160). The fire hearth was also lit for practical purposes of clearing smells and odours created by mouldy damp timbers (155) and also for the eradication of insects inside the house (165).

The moamoa, is a specially carved wooden frame, with painted symbols of the moon and stars (dots and triangles) similarly found in the malu (female tattoo) (155). One story I found made in reference to the moamoa, was that it was a place where the ‘life force’ agaga of a girl (which also had the form of a pigeon) was kept confined inside an ola (alive, life force), a medicinal bag traditionally used by healers. A powerful sorcerer, known within all Samoan families as the female progenitor called llamutu a le Tamasā; had refused to resuscitate the girl and restore her human form. In the progression of the story, the llamutu was consequently defeated by a clever and cunning male hero who climbed up to the top of the moamoa, and released the girl’s life-force from captivity. For his efforts, the hero proved himself as a worthy suitor and lived happily ever after with the young woman.

‘Captivity’ which is normally associated with warfare, alliance formations and aggrieved parties is embedded both in the architectural structure of the traditional Samoan house (moamoa) and more importantly in the restoration of life, where body and spirit are reunited. When chiefs and orators gathered for the Fonomanu (Gathering-Pigeons) it was to meet to prepare for war (152). The bird-like features attributed to human beings is synonymous with hunting and the differentiated roles that chiefs and llamutu hold in Samoan society. However, when families gather to make a formal apology called the Ifoga it is a deeply humbling plea for the

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53 Dr. Fanaafi, op.cit. p. 18.
54 The story is part of a written collection but I could not find the source of authorship.
55 llamutu: In Samoan oral tradition, she is a powerful sorcerer, ogre, from the matrilineal descent lines (Tamasā), considered as protectors of the wisdom and traditions of the chiefs and all male descendants (tama tane). Ibid, Mailo (1992). Moyle’s collection of music and stories (fagogo) referencing llamutu, closely associates them with the supernatural characters of female relatives such as a father’s sister and father’s sister’s female children.
56 In the mythologies and fagogo (performed stories) I surveyed, a young woman is often depicted as a lupe (pigeon). The moamoa’s structure was built to hold cultural wealth, although it could easily withstand the weight of a pigeon. The idea of being held against her will and being hopeful for a hero to battle for her freedom, might reflect an element of ancient Samoa in relation to the aumoega and the arranged marriages of women of rank. Fagogo and cosmological myths are endowed with the emotional trauma of characters lost in the bounds of courtship and marriage. Being freed from the moamoa would signify relief or freedom from obligatory responsibilities and their associated political or social alliances. The orthological (bird) symbolism is a recurrent feature of Samoan culture.
‘protection’ of the wrongdoer’s life. To exercise forgiveness, the families humbly kneel in full view of the public, while being covered by a fine mat. Samoans understand the importance of finding ways to resolve conflict and wrongdoing; a theme which was discussed by most of the participants in the home detention study.

Figure 3-2 Interior Shelving of the fale tele. Source Unesco 1992, p. 42.

3.1.5 Middle of house structure and cultural wealth

The highest level of the falettele, the roof apex (taualuga) central posts, upper shelving and lower levels of the inner structure are connected and provide storage for feminine and masculine cultural wealth. The entire lower ground floor is utilised for the formal accumulation and distribution of cultural wealth during important family and village events. As seen here in Figure 3.2 the fale tele has a sophisticated ‘shelving structure’ talitali and reaches to the highest upper level of the roof, closest
to the crowned area connected to the roof called the *taualuga*.\(^{57}\) A cross-sectional view (see Figure 3.3) reveals the simple yet sophisticated shelving structure, a construction which is installed only by the most highly skilled *tufuga* carpenters (166).

The human anatomy is represented in the main structure of the house. In Figure 3.4, I have sequenced the storage of objects anatomically beginning at the head and descending downwards. In replication of the range of cultural wealth that could be stored within the *talitali*, at the top of the shelf the most prized heirloom would have been the *Tuiga ‘headdress’* made of human hair. Interestingly, the dimensions of a singular strand of human hair were used as an ideal measurement of a strand of weave for a fine mat.\(^ {58}\) The association of *tuiga* to the *llamutu* or female progenitor as ceremonial headdress can be applied and worn by both female and male descendants of a family (152). Te Rangi-Hiroa (Sir Peter Buck) who studied closely the architecture of the Samoan fale tele in Eastern Samoa (American Samoa) also reported the design features that were concealed within the *moamoa*, a small cage-like compartment at the upper region of the shelving system; ornately decorated with feminine tatoo symbols such as the stars, birds and flowers; symbols which also feature prominently in the Samoan *malu* tatoo (155).\(^ {59}\)

The *so’a* or the shelving beneath the *moamoa* held household ritual objects such as fine mats, tapa cloth, body accessories like necklaces and whale tooth, and kava bowls for ceremonial events. A fine mat is symbolic of the *lagi* (heavens) and the genealogical links made through marriage and death thus reinforcing the social contractual agreements *feilo’aiga* (connections and relationships).

Fine mats are particularly important gifts *lalo* to Orators for their expertise in officiating formal ceremonies (167). As will be discussed in the following section, fine mats are used for important life events and are named in honour of an event such as birth (*ie fa’atupu*), marriage (*ie nofova’a*), or apology (*ie fa’amagalo*)

\(^{57}\) *Tuauluga*: specially tightly-plaited thatch used to crown the roof along the entire length of the ridgepole. Ibid, *Unesco* (1992).

\(^{58}\) Key informant interview, Vi Vailili (nee Seu Siavao), an experienced weaver in my family from Avao, Savai‘i.

\(^{59}\) Refer p.81 of Hiroa.
Cultural Capital

Epistemology Of The Interior Of The House & The Ritual Household Objects

Figure 3-3 Cross Section View of fale tele and interior shelving structure. Source Unesco, p. 47.

Figure 3-4 Storage of Cultural Wealth
The ‘ribs of the roof’ *ivi aso* represent Samoan maternal and paternal genealogical lineage (168). In the middle of the house, a hearth (*magālafu*) or a special fire place, spiritual wellbeing. The ‘skin’ metaphorically referred to as ‘clothing’ or ‘shield’ of a person’s higher self or beauty is associated with Samoan tattooing and the tools of tattooing.

The long-term accumulation of human and medicinal waste associated with chronic illness and palliative care has distinct linguistic registers within the Samoan language. The word *apulu* refers to the sticky coating of organic matter caused by perspiration and medicinal applications (plant and oil) which have accumulated over time. *Apulu tōfāga* is a respectful term that refers to the ‘primary site of illness’ of a chief’s family member (169).

At the lower level, is a special shelf called *sasaga* for the placement of drinking water containers (165) (not shown in Fig. 4.4). These cups are different from the cups discussed later where two sisters attempted to ‘capture’ *pu’eata* images of their brother with bamboo cups *ofe*. Although, not associated to what is normally considered as Samoan cultural wealth, the cups used in the story signify the variant ‘images’ of ‘family’ and the significance of *tautua* ‘service’ as a strong determinant of Samoan social identity, prestige and status.60

3.1.6 Summary

The main architectural features of the Samoan traditional house show how the important notions of humility, love, forgiveness and reciprocity underpin the traditional built environment. In the next section, I turn more specifically to the roles and responsibilities associated with the front, middle and back of house. *Tautua* or service to one’s family and community provides an even greater context by which the ‘care’ and ‘protection’ of the most vulnerable individuals is understood. This is important given the numbers of Samoans on home dialysis and home detention being care for by family members.

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60 I could not find any other references for the use of *ofe* (bamboo cups) as either ‘pu’eata’ or as important Samoan cultural objects (*measina*).
3.2 Section B - Epistemology of the Samoan Roles of Care and Protection

In Samoan society, leadership and authority is attained by ‘service’ tautua to one’s family, village and nation: “O le ala ‘i le pule ‘o le tautua” (the pathway of leadership is service). Social prestige, status and the accumulation of cultural wealth are some of the ‘rewards’ and ‘favours’ that individuals and their families can earn through tautua.

Individuality is acceptable within the collective nuclear (aiga lāpotopoto) and extended families (aiga lautele) (170). Samoan gendered arrangements are important, but overall underpinned by peace-making, traditionally the sphere of women; and protection, the traditional sphere of men (164). This is important when considering the obligations of ‘care’ and ‘protection’ whenever ‘familial space’ becomes an enclosure for the performance of service and duties; an important theme that emerges from the in-depth interviews provided by the participants of the home dialysis and home detention case studies.

The central tenets of tautua, ‘hard work’ and ‘contributions’ to the family, are facilitated by three important principles:

1) Respectful communication and proper acknowledgement of others, O fa’aaloaloga i le vā fealoa’i o tagata uma;
2) goodwill, compassion and generosity, O alofaaga lautele i so’o se tasi;
3) honoring of one’s leaders, lands and ancestral titles/names, O le mamalu i ona ao ‘ātoa ma ona lau’ele’ele faitele tau Suafa (152).

Simanu described five main forms of tautua that Samoan society places great value of importance: matavela (services associated with fire), matapalapala (services of harvesting), toto (services of protection) and taiupu (services of speech and communication) (170). I have attached a fifth tautua va tapuia, pertaining to a family’s ‘spiritual wellbeing’ (see Appendix 3.2 for a fuller description of the five listed services).

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61 Simanu’s comprehensive book is a Samoan text without English translation. The translation provided here is my own.
62 Mailo’s highly respected work is a compilation of contributions put together by knowledgeable Samoan chiefs and orators of Samoa. Most of the references in this chapter are from a later edition provided in Samoan and its English translation.
As set out in Table 3.1, duties and obligations are conceptually and systemically organised according to a range of anatomical, geo-mental, ethno-medico, bio-psycho-social and architectural meanings. These culminate in ‘family-centric’ dynamics and interactions that produce socially acceptable ‘goods’ and unacceptable ‘bads’; defined more generally within modern societies as social capital goods and services.
Table 3-1: Five Complex Forms of Traditional Social Duties for Samoan families that generate social capital in Aotearoa/New Zealand society

<table>
<thead>
<tr>
<th>Sphere and dynamic of Samoan social capital</th>
<th>back of house</th>
<th>middle of house</th>
<th>front of house</th>
</tr>
</thead>
<tbody>
<tr>
<td>most emulated Samoan ‘services’</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>tautua matavela</strong></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>service of earth oven umu</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>tautua matapalapala</strong></td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>service of harvesting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>tautua toto</strong></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>service of blood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>tautua va tapuia</strong></td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>service of prayers and fire hearth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>tautua faipu</strong></td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>service of communication ‘ava</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dominant activity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cooking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>planting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cooking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>planting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cooking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 anatomical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>impact on the body</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>reddened eyes “e velasia mata i aso ‘uma i le faiga a le suataute a le matai” ‘the eyes are scorched each day in the preparation of the chief’s meal’</td>
<td>sweaty forehead “ua susu le muahu ma mata i le faiga o taumafa a le matai” ‘the forehead is and eyes are drenched in the preparation of the chief’s meal’</td>
<td>muscle &amp; brawn “e lē mafai ona ‘alo i se mea faigatā, e tusa lava pe o’o i le oti, e lē fo’ia”. ‘nothing can deter you, even death’</td>
<td>serene spirit and emotions “fanaafi fa’amalama, tapua’iga o samoa” ‘fire votives, prayers and wishes for protection and wellbeing’</td>
</tr>
<tr>
<td>2 geomental</td>
<td>impact on the environment</td>
<td>fire pit, smoke, rocks</td>
<td>trees, plants, dirt, ocean</td>
</tr>
<tr>
<td>-------------</td>
<td>----------------------------</td>
<td>------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>3 ethno-medico</td>
<td>formal roles for economic, health, wellbeing &amp; social order</td>
<td>carer tausi</td>
<td>carer tausi</td>
</tr>
<tr>
<td>4 bio-psycho-social</td>
<td>family-centric characteristics</td>
<td>nurturance – nutritional and sustenance</td>
<td>physical – economic return and productivity</td>
</tr>
<tr>
<td>5 architectural</td>
<td>impact on household space &amp; function</td>
<td>preparation, processing, consuming</td>
<td>replanting, harvesting, storage</td>
</tr>
</tbody>
</table>
When applied to the two distinct domains of the traditional family dwelling ‘front of house’ and ‘back of house’, obligations and responsibilities are rendered into different tasks and obligations (Fig. 3.5).
3.2.1 Middle of house – social contracts

Ritual household objects
As highlighted in the previous section, cultural wealth is stored at the ‘middle of house’ (see also Appendix 3.2C with respect to the Samoan spiritual associations of this domain). In this section, I discuss the relevance of ritual household objects and their association to formal Samoan gendered arrangements and family obligations, particularly with respect to the care, protection and advocacy of those most vulnerable: the unwell (tausi ma’i), children (tausi tamaiti), the elderly (tausi matua), the deceased (se’etalaluma) and incarcerated (tagata agasala or pagotā).

Woven fine mats
As mentioned earlier, a fine mat is symbolic of the lagi (heavens) as well as the social contractual agreements made through marriage and death feiloo’aiga (connections and relationships). They help form the basis of commitment between spouses, parents and their children, and different groups within Samoan society.

The le Nofova’a (nofo, sit; va’a, canoe), is a finely woven mat ie worn by a woman to cushion the heart, after a long journey by sea and afterwards gifted to the navigator (tautai) for safe passage (158). This particular mat is an heirloom of bride wealth (153), symbolising the new journey with her betrothed partner in anticipation of new experiences. Similarly, the le Fa’atupu, is a mat woven over many years, crafted from a girl’s birth until she is of child bearing age and ready to marry. It signifies ‘growth’ of a family’s future offspring.

A mat that is an important symbol of ‘forgiveness’ and can be offered as an ‘apology’ in a formal ceremony of Ifoga is otherwise known as the le Fa’amagalo. The ‘apology’ is an enactment of communal restoration (family, village, state) of public good and forgiveness carried out within a few hours or a few days after an offense is committed. An offender and their family are required to congregate on site, at the home of the aggrieved party, and lower themselves to the ground. In a story about The House of Po and Ao, one of the five Samoan archetypal houses (See Appendix 3.1.2), lowered its ‘spears’ around its perimeter to allow Alo to enter and exit the house without harm. In doing so, the house showed deep humility and submission, thus demonstrating the ‘correct’ and ‘appropriate’ response to ‘offensive’ or
'defensive' attacks that was made wrongfully (171, 172). Moral messages that underpin this story or fagogo are a central function of all fagogo and these in turn provide a framework of guidance for individual day-to-day experiences. Appendix 3.4 Section 3.4C on Pu’eata is a story which provides a clear example of how a fagogo is used to highlight expectations and obligations within the context of ‘water images’ and ‘water pools’.

3.2.2 The Back of House - Care, Protection and Advocacy

In Samoa, families are encouraged to be vigilant in caring and tending to their lands and plantations, an indicator of social order and social cohesion. Family members involved in the care of the elderly, children and the unwell are often tasked with the messy and physical labour of food preparation as well as the tasks of bathing and housekeeping (refer to Appendix 3.2E).

The ‘back of house’ traditionally includes physically laborious and messy duties associated with planting (fa’atoaga), fishing (fagota) and fire ovens (umu). Although, the production of cultural wealth (toga, tapa, coconut oil) pae ma le auli and peace-making are specifically associated to women; and protection malu ole atunu’u to men they are also duties which can induce pain to the body. The obligation to protect one’s family malu a le aiga, enforce rules against wrongdoers and the incarcerated, defend one’s nation in times of peace and war are normally considered masculine responsibilities; whilst the obligations to care for the unwell, children, elderly fall within the feminine domain.

The most common and often menial duties at the back of house are those, which literally and metaphorically cause ‘soreness of the eyes’ because of their association with smoking umu pits, used for food preparation and cooking. Tautua Matavela (eyes-scorched) is linked to the saying, “Ua mu mata i le faiga o suavai a le matai” (The eyes are burned from preparing the umu for the chief). Similarly, Tautua Matapala (brow-drenched) specifically involves laborious and physical duties provided by tulafale (Orators) such as harvesting, plantation, fishing and livestock. Those who show hard work are rewarded with toga and oloa (masculine cultural

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63 Tautua Matapala, is normally accorded to Tulafale (Orators), Simanu, p. 112.
wealth, titles, money and goods). “Ua susū le muāulu ma mata i le faiga o taumafa a le matai” (The forehead is wet from preparing the chief’s meal).

_Tautua Mamao_ (Service from Afar), refers to individuals living away from their family lands or living abroad who contribute to the social capital and wellbeing of the family.\(^{64}\) This is particularly relevant for family members sending remittances of cash and commodities from overseas to the Samoa homeland.

### 3.2.3 Summary

The roles of care and protection in Samoan culture are underpinned by ‘service’ and the social contractual agreements built around family relationships. Ritual household objects such as _toga_ or fine mats are Samoan cultural wealth linked to the middle of house are gifted to celebrate and mark key life events such as birth, marriage and death. Gendered roles are often divided into ‘protective’ (male) and ‘caring’ (female) duties at the back of house that are often repetitive, menial and physically demanding. Overall Samoans are taught that ‘service’ is more than the fulfilment of individual responsibilities, but that it can lead to opportunities to gain status, cultural wealth and recognition within the Samoan hierarchal structure.

In the next section, I consider the relationship between Samoan metaphorical language and the way that Samoans traditionally made sense of their day-to-day experiences within the built-environment by observing naturally occurring phenomena such as the ocean tides and winds. The ability to weave metaphors enables familial and political leaders to forge goodwill, address disputes and foster social cohesion between family members and other kinship groups, a task which is formalised at the front of house _(_luma fale_) and a service carried out by leaders and orators _Tautua Upu_ (Service of Words).\(^{65}\) These provide families with a unique way of understanding illness events and conflict as well as forming strategies for the preservation, maintenance and promotion of wellbeing. The same skills are used to develop strategies to negotiate relationships with those outside the family such as state and civic societies.

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\(^{64}\) Ibid, p. 118. The homeland, Samoa refers to Independent Samoa (formerly Western Samoa) and American Samoa (Eastern Samoa).

\(^{65}\) Simanu, op.cit p. 108.
3.3 Section C - Epistemology Samoa Communication – Tides & Winds

3.3.1 Introduction

This section has presented a range of ancient Samoan names of ocean tides and winds. In raising some specific questions about families living with home dialysis and home detention, I wanted to highlight the way in which illness and imprisonment experiences can be conceptualised through an indigenous Samoan linguistic and metaphorical framework. This will assist with the analysis of many of the experiences that participants report in the results chapters. As will be shown later in the results section, water and healing are closely connected, as are tides and winds, and these connections helped some participants in the study to make sense of their experiences.

The *fale tele* (as described in the previous section) is like an ocean platform where a very skilled orator has the exceptional ability to summon the winds (*Matagi o Samoa*) and to draw the tides (*Tai o Samoa*) in order to illuminate an issue or challenge a situation. Winds are believed to have their origins in the spirits of deceased ancestors and tides from the physical remains of ancestors left behind in the shape of coral and volcanic rock. In the following sections, I focus on some of the important aspects of Samoan traditional oratory and how Samoan social obligations within the built environment are directly associated with the natural environment of the ocean tides and winds. Samoan household spaces are distinguished by what people do’ and ‘say’ (social obligations) and the environmental motifs that is associated with those spaces (geom mentality). Figure 3.6 illustrates perhaps one of the greatest advantages of the wall-less structure of the traditional Samoan house, which is its wide-open view from the inside to the outer landscape and visa-versa.

These provide a range of meanings that will be used later in the analysis of the participants' photographs and narratives.
3.3.2 Front of house – communication, a way of singing

At front of house, the ‘services’ of Tautua Upu include the skills of communication - oratory, debating and decision making’ (tofa and moe). Social contracting, alliance formation, negotiated terms between one family and another extend into multiple levels of the Agan’u. The performative acts of narrating, and articulating village honorifics and connections in a song-like chant (fa’alupe, pidgeon-like) are at the heart of the interactions between families. A speech is metaphorically described as a spear (Tao) or a net (Upega) (152). For this reason, an orator must also have the skill at the front of house to facilitate traditional exchanges of gifts (sua, inati, lafo) at the middle of house (refer Figure 3.4 above ). When spears are thrown and nets cast out, a competitive deliberation (fa’atau) is held to find the most eloquent speaker. The ‘eliminatory process’ of debating is more significant than the main speech (failauga) that is being contested, because it is also seen as a ‘sacred’ (paia) process: “E paia le fa’atau, ae le paia le lauga”, (Sacred is the debate, not the
In Samoan dance performance, a similar eliminatory process known as the sivaloa is held to find the best dancer to take centre stage (taualuga). Similarly, the “deliberation” (siva loa) rather than the taualuga is given significance.

Traditionally, only the most seasoned orator with skill and cunning can perform a complex “dance of intimidation” and be successful in the elimination process. The orator is a navigator, who can best steer the course in unpredictable waters, thus, the saying, “Fili i le tai se agava’a,” (Seek from the ocean the best navigator). Linguistically an orator’s staff (to‘oto‘o) can be used offensively and defensively to form the flight, parry, or the severity of a speech in order to influence an audience. The more eloquent and innovative their use of metaphorical phrasing, the more likely they are to consume their competition. By drawing on the richness of the environment an orator can heighten or diminish the tensions between different parties. For example, the saying, “Ua lutaluta le savili, ona sisi lea ole la’a‘a” is translated, signals to those listening that a more aggressive approach is needed to resolve a sensitive and difficult issue. “The winds are shifting; therefore, raise the sails made of sennitt!” In the context of healing and care giving, a staff (spear, tao) can also transform as a walking aid for a Taulasea (traditional healer) to support a patient (spiritually and physically) over the duration of illness.

To Fa’alupe (recite, in song-like chant; a lupe, pigeon) is to pronounce the honorifics of a family’s titular and village titles, original ancestral houses (maota or laoa), or the sacred sites or residences for burial (lagi for funeral events). The expertise of knowing the historical and genealogical connections between Samoan families ensures that traditions, which legitimise and foster social cohesion involved in the celebration of marriage, political alliances and village ties are preserved and maintained. There are many analogies and symbolic references to orthologic (bird) observations. Associated with the raised hunting platform (tia) used to snare pigeons in the bush, the grave site where a chief’s bones are permanently interred is also known by the same word (tia). The sleeping place of a chief (tofaga), also describes the sleeping place of a pigeon (tofaga). A family gathers together, much for

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66 Malifa defining the Sivaloa.
67 The Taualuga is the final siva (standing dance) that completes a period of entertainment performed by a high-ranking male or female.
68 Also “Sa‘ili i le tai se agāva’a”. Supervision Tupuola, July 2006.
the same reason that birds build nesting roosts for the protection and nurturance of their offspring.

Figure 3.7 (below) brings together the traditional social obligations discussed earlier and their associated Samoan geomental motifs, which are underpinned by the natural environment. This summarises the way in which the traditional built environment is mostly determined by family-centred services and how social obligations are also used to preserve, maintain and continue the important values and traditions associated with Samoan cultural capital at the middle of the house.

In the following sections, I present a metaphorical framework based on ancient Samoan ocean tides and winds, and use these to reframe some of the conceptual and practical issues related to my investigation about Samoan families’ experiences of home dialysis and home detention. To assist with this, I commissioned artworks
from family and friends who through their paintings and sculptures have offered their visual interpretations of the tides and winds. I begin firstly with the Samoan ocean tides and then in the following section with the Samoan winds.

### 3.3.3 Samoan ocean tides – *Tai o Samoa*

#### Table 3-2 Ocean Tides

<table>
<thead>
<tr>
<th>Tides of Samoa (175)</th>
<th>Meaning</th>
<th>Meaning (Key Informants: Tuitama Talalelei; Tanuvasa Ioane)</th>
<th>Social Dynamic (Conceptual Analysis to apply to Photographs &amp; Narratives)</th>
<th>Tidal comparison (176)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Taioalo</td>
<td>O le tai e manino luga, ae vilivili lalo</td>
<td>From above the tide is calm and a whirling riptide below.</td>
<td>Potential fragmentation, oppositional</td>
<td>Tide rising in morning dawn</td>
</tr>
<tr>
<td>2) Taifula</td>
<td>Tai e le sua tetele le pe tele</td>
<td>Neither high or low tide, difficult to diagnose a wound getting better or worse.</td>
<td>Doubt prevails, confusion.</td>
<td>Falling tide but still deep.</td>
</tr>
<tr>
<td>3) Taigau</td>
<td>Tai ua faasalo ina mau i tai</td>
<td>Broken fever; coolness of the souls of the feet.</td>
<td>Gradual restoration and return to normality.</td>
<td>Turn of tide.</td>
</tr>
<tr>
<td>4) Tailomaloma</td>
<td>Taimalū</td>
<td>Await your moment, or await your time, or opportunity.</td>
<td>Force or compulsion will only exacerbate the situation.</td>
<td>Spring tide.</td>
</tr>
<tr>
<td>5) Taimasatō</td>
<td>Tai ua pe eelele</td>
<td>Petrified landmass, vanquished tide.</td>
<td>Exposure to sun, wind and rain generates decomposition and odours.</td>
<td>Very low tide.</td>
</tr>
<tr>
<td>6) Taisualolo</td>
<td>O le tai ua lolo ma sua enaena</td>
<td>Surface is smooth as glass.</td>
<td>Transparent, yet caution required</td>
<td>Moderate tide.</td>
</tr>
</tbody>
</table>

The six tides (summarised in Table 4.2) are: Taioalo, Taifula, Taigau, Tailomaloma and Taisualolo (See Appendix 3.3.3 for more detail). Ocean tides are used to understand the effects of illness and to measure changes over time. At the front of house, orators may use these metaphors as a way of interpreting different dynamics between Samoan hierarchical groupings and to highlight the emerging outcomes associated to decisions made by those in authority.

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69 176. Tuvale T. An Account of Samoan History up to 1918. Wellington: Victoria University; 1918 [cited 2007]; Available at [http://nzetc.victoria.ac.nz/](http://nzetc.victoria.ac.nz/). A comprehensive list of Samoan tides and winds is provided by Tuvale. Another list, is provided by Mailo’s earlier version (1972). The tides selected here were taken from Mailo and investigated further by the researcher with key informants.
Tai-o-alo (tide-of-children) reflects a calm surface above, and an ominous whirling riptide below. Its emphasis is on leadership, where there might be coexisting and competing dynamics: calm leadership (above) and agitated restlessness (below). Tensions that exist between the hierarchal structures of Samoan traditional society (atunu’u). These can involve conflicts between leadership and subordinate groupings; or groups with competing interests and demographics: elderly (tagata matatua) and youth (talavou); Chiefs (Tamali’i) and Orators (Tulafale); untitled men (aumga) and titled chiefs; and older women (Tausi ma Faletua) and younger/unmarried women (auluma) and healers/midwives (taulasea/fa’atosaga). The dynamics can also arise from institutional arrangements: doctors and their patients; police and detainees; teachers and students; employees and employers. As shown later in the results chapters, Samoan families living with public services such as home dialysis and home detention are required to negotiate resources with their respective public authority and deal with issues of adjusting to the formal obligations of care and incarceration.
Taifula (tide-wound) is neither a high tide nor low tide. Doubt prevails, and it suggests confusion and potential complications. The analogy of disease and the swelling of a wound, the discomfort of pain, and the inability to feel relief are analogous to the phenomena of recovery and healing. Fula (wound, scab or swelling) is an inescapable reality of being human; the only certainty is that when illness or trauma occurs there are moments of difficulty when the unknowable takes over. It is difficult to determine whether a wound is getting better or getting worse. Careful reading and patience is required to know which way the tide is turning. Changing tides are often unpredictable and individuals and their families should exercise patience, endurance and faith that relief will come.
Taigau (Tide Broken Fever) is a strong tide that having reached its maximum height gradually diminishes and eases. Two distinct meanings are associated with this tide. The first refers to a high temperature fever experienced in sickness, which when broken, gradually decreases to a normal level. The second meaning refers to figota (the harvesting of sea creatures), in particular, a mollusc sea slug called the gau\(^70\) (green limacoid, Dolabella rumphii).\(^71\) The sea slug is most often harvested by women at night with bare feet. Using the soles of their feet to feel for the slippery silky slug beneath the sand, it is collected and then eaten as a delicacy. This tide depicts the natural ability of the human body to heal and to restore itself to recovery from illness, shock or exhilaration and return to normality and the continuance of life.

How do the families cope with the extreme situations of chronic disease and home confinement by surveillance? What were the highest stress points? When and what was it that made the worse times the worse times? What happened that helped them to return to an increasing level of wellbeing?

\(^{70}\) Gau may have a phallic association to the Samoan word ga’au (penis), though no reference could be found for any medicinal use of gau for sexually related illnesses.

\(^{71}\) Patent search reveals that this sea slug produces anti-inhibiting properties for the cure of neoplastic diseases (new cancer growth) in leukemia.
The fourth, *Tailomaloma* (Awaiting), is a tide that moves quietly, and not strongly. A tide that promises hope and prosperity. “Await your morning” (*sema sou taeao*) is an appeal for patience and diligence, trusting in the future. Samoans adhere strongly to the rewards of hard work and effort through service (*tautua*) to one’s family, village and leadership. Altruistic acts of kindness, particularly in relation to the care of the chronically ill and the most vulnerable often involve long-term commitment and sacrifice. This tide provides encouragement to persevere for the completion of the task. What motivates carers and sponsors to carry out their obligations? How do those on dialysis and detention resolve the difficulties of their circumstances?
Fifth, *Taimasatō* (Tide Dead) is a tide that washes to the end of the shoreline, vanishes and forms sand dunes, the rising expansion giving the appearance of pregnancy. Another meaning is an extremely low tide that causes extensive exposure of rock and plant life to the sun, wind and rain, thus producing a sulphurous and putrefied smell. The word *tō*, has three distinct meanings: dead and lifeless, steep cliff or cavernous hole, and pregnancy. In Samoa, there are two underground caverns in the coastal village of Lotofaga. One of the caves is named *Tōsua* (*sua pe a sua mai le tai*, water holding), and is filled with water by the incoming tide. The other cavern, named *Tōlesua* (no water) is never filled with water. Interestingly, this tide provides a powerful metaphor for the dialysis process, contaminated blood filling and being cleaned between two caverns; and like home detention, of being held in one cavern and being able to come and go as in the other cavern. Those who live with these imposed conditions are often exposed to many other medical and social problems. How and when do they feel the most exposed?
Taisualolo (Glassy Tide) gains its name from the fineness of pure coconut oil (lolo, suau’u) and the textured smoothness of the surface. The absence of impurities in high quality oil produces a unique translucency. When impurities are present they collect at the bottom of the oil and discolouration is easily detected. The manufacture of high quality oil is not very complicated but requires time, dedication and attentiveness. The absence of movement produces a very calming effect (malū) of this wave, but the refracted reflection could suggest the presence of micro-organisms in the ocean. An important issue is the quality of life for those on home dialysis and home detention. What are these and how do they illuminate problems that impact their quality of life?

3.3.4 Samoan winds – Matagi o Samoa

Winds are equally important to Samoan understanding of social reality. As summarised in Table 4.3 the winds are: Fa’asulu, Fa’atiumatagaitogaina, La’i, Matagifanua, Si’umaouli and Tuaoloa. Identified as having ‘spiritual’ presence of deceased family members, winds replicate restlessness and unfulfilled human accomplishments (23). At the front of house, different winds are used by orators as
provocative linguistic techniques and strategic approaches to challenge one another during deliberations. (See Appendix 3.3.4 for further notes.)

Table 3-3: Samoan Winds

<table>
<thead>
<tr>
<th>Wind</th>
<th>Social Dynamic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1) Faasulu, Unrelenting Wind</strong></td>
<td>Storm seaward straight, running for one’s life; strongly opposed view directed from the back</td>
</tr>
<tr>
<td><strong>2) Faatiumatagitogaina Unteasing Wind</strong></td>
<td>Winds while diving at sea. The difference between diving equipped with a spear or a stick; hedging around the rocks or sturdy blows. Being tested and provoked; or holding ground.</td>
</tr>
<tr>
<td><strong>3) La’i, Passing Wind</strong></td>
<td>From behind the back of the houses. Displaying bravery and applying ineffective strategies to an old problem. Like beating a dead horse.</td>
</tr>
<tr>
<td><strong>4) Matagifanua, Rejuvenating Evening Wind</strong></td>
<td>Cool, still breeze in the evening, from the sea. Still that no leaves are disturbed. Mostly welcomed by the elderly.</td>
</tr>
<tr>
<td><strong>5) Si’uamouli, Unpredictable Wind</strong></td>
<td>Wind that occurs without warning; creates panic and alarm.</td>
</tr>
<tr>
<td><strong>6) Tuaoloa, Gravely Cold Wind.</strong></td>
<td>Extremely cold wind. Threat to life. Deathly cold from the grave. Weakens human beings; makes wild the beasts. Mostly feared by the elderly.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wind</th>
<th>Social Dynamic</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
<td><strong>5) Si’uamouli, Unpredictable Wind</strong></td>
<td>Wind that occurs without warning; creates panic and alarm.</td>
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<tr>
<td><strong>6) Tuaoloa, Gravely Cold Wind.</strong></td>
<td>Extremely cold wind. Threat to life. Deathly cold from the grave. Weakens human beings; makes wild the beasts. Mostly feared by the elderly.</td>
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<table>
<thead>
<tr>
<th>Wind</th>
<th>Social Dynamic</th>
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<tbody>
<tr>
<td><strong>1) Faasulu, Unrelenting Wind</strong></td>
<td>Storm seaward straight, running for one’s life; strongly opposed view directed from the back</td>
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<tr>
<td><strong>2) Faatiumatagitogaina Unteasing Wind</strong></td>
<td>Winds while diving at sea. The difference between diving equipped with a spear or a stick; hedging around the rocks or sturdy blows. Being tested and provoked; or holding ground.</td>
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<tr>
<td><strong>3) La’i, Passing Wind</strong></td>
<td>From behind the back of the houses. Displaying bravery and applying ineffective strategies to an old problem. Like beating a dead horse.</td>
</tr>
<tr>
<td><strong>4) Matagifanua, Rejuvenating Evening Wind</strong></td>
<td>Cool, still breeze in the evening, from the sea. Still that no leaves are disturbed. Mostly welcomed by the elderly.</td>
</tr>
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<td>Wind that occurs without warning; creates panic and alarm.</td>
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<td>Extremely cold wind. Threat to life. Deathly cold from the grave. Weakens human beings; makes wild the beasts. Mostly feared by the elderly.</td>
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</table>
The Faasulu (Unrelenting Wind) is associated with the urgency to escape from a force of an unrelenting wind. Associated with a storm or hurricane, it has a pervasive and enduring force that is both direct and persevering. When used as a linguistic technique, fa’asulu confronts in a very direct way, to extrapolate the core issues. “Fana tonu le malama,” (aim directly at the intended target and fire) is a strategy of ‘talking straight’, an approach which is easier for some people than it is others. In the context of thinking about the institutional arrangements associated with home dialysis and home detention, do families themselves feel able to talk directly to the authorities? Are there pressures they experience when the additional stressors of being at home make life more difficult? What strategies do they employ to escape the pressures that arise?
The second wind, *Faatiumatagitogaina* (Rough Diving Wind) is a wind that penetrates very rough and choppy ocean tides. In applying the meaning of this wind to a person diving out at sea, they show no hesitation about entering unwelcome waters (*fagota ile sousou o sami*). Instead, they demonstrate spontaneity and courageousness without surrendering to anxiety or fear. It is synonymous with someone being correctly equipped to hunt using a massive spear (*matatao*) hence the saying, “*Fagota i le Sao*”, rather than hedging around the rocks with a small stick (*fasi la’au* or *matalaau*), or poking without purpose and direction. This approach produces positive outcomes, despite the extreme challenges, which appear to be insurmountable. If families are dealing with tough circumstances, how well prepared are they to deal with issues of chronic illness, end of life, transplantation and the stigma of imprisonment?

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72 *Fagota i le Sao*: Diving and fishing of the type described here is specific to using a small spear which one pokes in amongst the rocks and coral in search of octopus and eels.
The Laʻi (Passing Wind) is a wind that has passed by, having lost both momentum and velocity. Wind can be useful in certain circumstances, but not when it is blowing in the wrong direction or at the wrong time. Hence, the saying, “Ua tatā tua o Fatutoa le Laʻi o Puava”; the opportunity has passed, no point pleading for that which has gone. Attempting to make up for the loss of something that is unattainable is pointless and to be discouraged. Chronic illness and wrongdoing can make people reflect about what could have prevented them from requiring dialysis or losing their freedom because of a crime they committed. Grief and loss is a normal part of the course in coming to terms with how life used to be.
Matagifanua (Rejuvenating Evening Wind) is an evening wind that cools, rejuvenates and reenergizes the body. It is most appreciated for revitalizing elderly folk. It is a refreshing evening breeze (O le sau o le afiafi, matagi malū) that enables the elderly women (lo’omatatua) and elderly men (toeaiina) to relax and rest. How do families ward off stress, anxiety, sleeplessness and worry? What strategies do they employ to help them feel rejuvenated and revitalized, particularly while responding to the weight and burden of dialysis and electric monitoring?
*Si’uamouli* (Shocking Black Wind) is extremely unpredictable and causes illicit shocking results. Appearing without warning, there are few climatic indicators or warning signs, although they are mostly connected to storms and torrential hurricanes. In a formal setting, a speaker makes an unsolicited attack or comment, which causes major alarm with no apparent reason or provocation. Dialysis is a lifesaving intervention without which a person is likely to die from kidney failure. How do families recover from the shock of a life threatening disease? How does a detainee integrate back to the community after causing harm to a person victimized by their crime?
The wind mostly feared by the elders, because of its extreme coldness, is the *Tuaoloa (Depth of the Grave)*. The saying, “E mama’i ai tagata, ae malolosi ai manu,” (the wind that makes people sick, but strengthens the beasts) is historically known as the origin of certain fatalities of the most vulnerable population, specifically the elderly and young children. Wellington is known notoriously for its cold winds so how do those confined at home on dialysis cope with the coldness? How does a detainee cope with the barriers of unwanted disapproval or violence at home?

### 3.3.5 Summary

This section has presented a range of ancient Samoan names of ocean tides and winds. In raising some specific questions about families living with home dialysis and home detention, I wanted to highlight the way in which illness and imprisonment experiences can be conceptualised through an indigenous Samoan linguistic and metaphorical framework. This will assist with the analysis of many of the experiences that participants reported in the results chapters.
4  RESEARCH METHOD

In this chapter I will outline the community-based participatory process that brought together a range of advisors and participants for my PhD study. I held consultative meetings with this external advisory group of advisors and cultural experts and this helped to contribute to the development of my epistemological framework, pilot study and participant recruitment. I will also present the process of ethical approval and the mixed methods approach I used including photo voice, visual diaries, key informant interviews and data analysis.

4.1 Community-based participatory process & the PhD advisory group & formative reporting

Given the paucity of available information about home dialysis and home detention amongst Samoan families, I approached key individuals who were specialists in their fields about the viability of becoming advisors for my PhD study (See Appendix 4.1). I then invited them to a series of consultation meetings that were conducted during 2005 and 2006 at the University of Otago, Wellington for the purpose of gathering relevant information to design and develop the methodology for this study. In total there were up to eight advisors involved\(^4\) as well as my two university supervisors. I was able to host the advisory group and maintain contact with individual members with funds from the New Zealand Health Research Council who provided me with the Career Pacific Award PhD scholarship.

I maintained email contact and held two advisory group meetings over May and October 2006. Advisory members provided invaluable background information about the range of evidential sources that I would need in relation to important aspects of the research and strategies of a ‘mixed method approach’ in relation to: participant recruitment, interview schedules and organisational arrangements (see Fig 4.1).

\(^4\) Appendix 4.1, List of Advisory Group Members and Informants the researcher met in the early planning stages of the study. One advisor was a senior clinician from the Wellington Hospital Dialysis Unit; another was a senior manager from the New Zealand Prison Service and two senior lecturers of Samoan culture and language were from the Va’aomanū, Department of Pacific Studies of Victoria University, Wellington. Also, I was fortunate to have the support of an authority on Samoan music and fagogo (folklore/stories) from the University of Auckland. A regional public health advisor also became involved because of his recent work with secondary school students using Photovoice and a colleague Samoan social worker from a Pacific non-governmental organisation.
4.1.1 Samoan cultural supervision and oral traditions

One of the key areas of concern identified at the beginning of the study was the need for cultural supervision and advice. My Samoan cultural advisors encouraged me to construct an epistemological framework that could be used to analyse the data when the field work interviews were completed. Following the recommendation of my colleagues and family, I approached Lavea Tupuola Malifa, Senior Samoan Lecturer at Victoria University of Wellington, an expert of the Samoan language and protocols. Lavea assisted me to interview two of the elderly male Samoan participants of the dialysis study and three Samoan orators from my family (Tuitama Talalelei Tuitama, Si'ufaitoto'a Simanu Ieremia and Tanuvasa Ioane) helped to provide important translations about Samoan ocean tides and winds, a key component of the epistemology for the study. Associate Professor Richard Moyle, an accomplished ethnomusicologist provided feedback on two of my epistemological chapters, particularly in relation to Samoan etymological meanings and fagogo (fables or folk-

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75 Ata (Family 1) and Olo (Family 3).
I maintained on-going contact with individual advisory members throughout 2007 and 2008 and sought guidance and assurance about various aspects of the study, although I have yet to update them about the latest progress in the study. I intend to do this when I have submitted my thesis.

Lavea worked with the National Turnbull Library to curate the *Va’aomanu* Exhibition of colonial photographs taken in Samoa during the British, German and New Zealand occupations and administrations. I surveyed the photographs of this collection at the National Library and one particular photograph dated around 1880s to 1890s of an early indigenous Samoan building (Photo 4.1) caught my attention. The minimal occupancy of space and the absence of furnishings highlighted the use of space to mediate social relationships, social order and cohesion. Without the distraction of physical household furnishings that is ordinarily found in Aotearoa/New Zealand homes, the Samoan *fale* Samoa represents the unique use of domestic space, where the cultural frameworks hold unique meaning and purpose.

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76 Fagogo are used as ways to depicting behavioural and moral principles. See Chapter 3 Epistemology and Appendix 3.4 *Pu’eata* – Capturing Pictures.

77 Acknowledgement to Peter Ireland, Curator of the Art Gallery, National Library for his assistance and guidance in relation to the *Va’aomanu* photographs. The collection can be accessed online on the National Library website.
Photo 4.1 also served as an inspirational anchor and a building framework for the analytical component of the study.\textsuperscript{78} Further research would resolve the mystery of the contents wrapped inside the woven mat stored within the upper interior shelving (\textit{talitali}) infrastructure of a Samoan building. It is a reminder of a dream I often had of human bones being stored for safe keeping in the attic of our Wellington family house. Albert Wendt’s novel “\textit{Pouliuli}” makes reference to bones stored this way (178) and it is a remnant of the memory of an ancient Samoan cultural practice which is supported by the continued custom of placing family graves in close proximity to family dwellings. This image began to form a backdrop for the way in which a photographic methodology might illuminate the stories of the participants from my two studies. My Samoan advisors agreed that a Samoan conceptual framework with which to view behaviour, attitudes and beliefs of Samoan people in Aotearoa needed to be embedded in the methodology and analysis, so that the information from the Samoan families of the study could be treated authentically and presented in a way that would be understood by non-Samoans.

The utilisation of Pacific paradigmatic models has continued to have an important place within the New Zealand public health sector in response to health policy and workforce capacity over the last four decades (179-181). From the late 1980’s Inquiry by the Royal Commission on Social Policy, Pacific communities voiced their concerns about rising costs for primary health care and the increasing importance of Pacific indigenous healing practices to families in Aotearoa (182).

Two such examples of a Pacific cultural model adapted for the health sector are the Fale Fono Model (Figure 4.2) developed by Pulotu Karl Enderman (183) and the “Flax-roots” Model produced by the Pacific Unit of the New Zealand Health Research Council (Figure 4.3) (184). The former model was originally developed for mental health practitioners, the latter for Pacific student mentoring.

\textsuperscript{78} Photograph from the Va’aomanu Exhibition. Possibly part of a collection of photos taken by New Zealand photographer Alfred James Tattersall who based in Samoa since the late 1870s.
Figure 4-2  *Fono Fale* Model. (Source: Alac p.115 Alcohol and Other Drug Use and Pacific People in New Zealand. Chapter 7, Teaching Guide.

The HRC’s Flax-Roots Model of Mentoring

Figure 4-3 Health Research Council New Zealand, 2006
4.2 Multiple-case study approach

It became increasingly obvious that an empirical study into the contemporary phenomena of public provided services within an ethnic familial context could involve many lines of inquiry. A multiple case-study seemed a suitable way of investigating relatively unknown areas: “…especially when the boundaries between phenomena and context are not clearly evident” (p. 13) (185).

The value of being able to explore aspects of the study with an advisory group was that they helped me to reflect and to refine four important domains of knowledge that would be important in the study. Figure 4.5 sets out the four domains.
Interestingly, a case-study can be utilised as a general strategy that brings together a mix of qualitative and quantitative evidence so that the broadest range of historical, attitudinal and behavioural issues can be explored (185) (p. 92). The advantage of this: “…allow[s] several possible applications to explain the causal links in real-life interventions that are too complex for survey or experimental research approaches” (185) (p.14).

Yin provides a model that emphasises the importance of triangulating multiple-sources of evidence to highlight lines of enquiry that might be pertinent to the study and more importantly where similar facts can increase the levels of data reliability (p. 93) (185). Through this approach the lines of enquiry are brought together to “converge”; the opposite can occur where ‘differences’ are highlighted through “non-convergence” and analysed separately to draw different conclusions. I applied the “convergence model” (Figure 4.6 below), as a way to examine the similarities between home detention and home dialysis based on characteristics such as demographic background, family composition, participants access to public and community services, use of household space for public services, ethnic and cultural values, and complications with the provision of public services at home.

However, the two case studies also differed in unique ways and therefore had to be treated separately and assessed on the basis of their own results. In this context, data is treated as ‘non-converging’ (Figure 4.7 below). Within the study, differences were found: institutional arrangements, background literature and official reports,
regulatory mechanisms, utilisation of private spaces at home for public services, family circumstances, problem-solving approaches and issues of stigmatisation.

For practical reasons, my family advisors, key informants and supervisors recommended that all outgoing and incoming communication with the participants (phone, email and letters) be separated. This way I would avoid any complex cross-referencing that could lead to confusion between the two case studies.
There are however several misunderstandings of the use of the case study method. In an illuminating article Flyvbjerg reframes the widely held criticisms made about the case-study method (see Appendix 4.2) (186). As Flyvbjerg highlights, concrete context-dependent knowledge is very valuable for understanding human affairs. My decision to examine two case studies was to compare two different context-dependent situations to generate some new insights about the way in which home-based services have an impact on the household behaviour, culture and domestic economy of Samoan families. The intention is not to generate generalisable knowledge about home dialysis and home detention, but to highlight characteristics about home-based services which may be misunderstood and unknown. Flyvbjerg also points out that case studies are particularly useful for falsifying preconceived notions about certain phenomena. Because there is a major paucity of literature and information about home dialysis and home detention, firstly, as home-based services and secondly, as services utilised by Samoan families, it is very difficult to quantify intuitively or empirically, what notions and preconceptions that I as a researcher would bring to the study; or where, during the case study process these would be identified and responded to. While it would be desirable to make predictive and theoretical hypothesis about the two case studies I intend to investigate, it would be difficult to do so, because the processes for each case differ in terms of complexity and variability. Instead, I intend to look at each case study in its entirety by comparing the outcomes and consequences of both cases, which will then assist me to draw conclusions about home-based services, specifically as they impact Samoan families.

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<tr>
<th>Non-convergence of Multiple Sources of Evidence</th>
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<tbody>
<tr>
<td>Interviews</td>
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<tr>
<td>Survey</td>
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<td>Documents analysis</td>
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<td>-&gt; findings</td>
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<td>-&gt; findings</td>
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<td>-&gt; conclusions</td>
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Figure 4-7 Non-convergence of evidence (Yin, p. 90).
4.3 Photomethods

4.3.1 Literature search on Photomethods

When I began the study using Photomethods there was no available photographic guides about how to conduct research using cameras specifically with Samoan participants. I was particularly interested in how photography could be used to record ‘sensitive’ and ‘private’ issues associated with chronic illness and prison incarceration within ethnic populations.\(^{79}\)

Samoan people as subjects, historically have been the focus of many photographs and discourses, a subject which I was interested in but was restricted by time and space to include in this thesis (see Appendix 4.3: 1A and B). Articles and books about the images of Samoan people were reviewed. These were mostly based on the work of colonial photographers in the Pacific and the proliferation of Pacific images for western publications and serial magazines (see Appendix 4.3.1D).

I was also interested in the historical development of biometric typologies in the fields of criminology and medicine, from the early period when photographs were used formally as ‘legal’ documentation as mug shot and medical file (see Appendix 4.3.1C). Photomethods became a critical area of academic debate in the 1930s amongst anthropologists and sociologists who challenged the traditional approaches of observational research and the wider application of visual methods to investigate culture and human affairs (see Appendix 4.3.1E and F).

A search on the word ‘photographic methods’ highlighted the way that visual images are able to: illuminate social phenomena (187-193); recover information that may have been lost (188, 194); produce unique datasets and diverse phenomena (195) that would not have been found (189); and make historical sociological data visible that would not have otherwise been found through traditional qualitative surveys and interviews (196). Visual methods\(^{80}\) can also provide a vibrant alternative to “textocentrism” which is the privileging of text, writing and the lettered word, or verbal

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79 I took up a stills photography course in the early part of beginning the PhD with The Learning Connexion, Island Bay, Wellington. It involved learning about the mechanics and uses of the camera, processing and developing film in a dark room.

80 Visual methods can extend beyond photographs and includes other modes of expressions such as painting, sketching, film making, graphics design. However the literature analysis was primarily about photography and camera use by participants to express their stories and views.
and observational data; therefore, highlighting everyday experiences across different health environments (193, 197-201) (refer to next session and Appendix 4.31H).

4.4 Photovoice

4.4.1 Literature Review of Photovoice

I reviewed approximately 37 articles on studies that utilised ‘Photovoice’ and ‘Photomethods’; 22 of which were studies about diverse ethnic communities’ utilisation of public services; no studies were found about home dialysis, home detention or Samoan communities. The most relevant articles that I thought would be useful for my two case studies are discussed in the following section.

A search of Photovoice highlighted that it is a methodology that can be used in conjunction with several other methodological approaches: content analysis (202, 203), photo elicitation (195, 204, 205), grounded theory (206); participatory action research (207, 208); focus groups (194); dyadic interviews (203); participant diaries (189, 209); and understanding social practices within geographical locations (210).

A methodological use of photographs for research is Photovoice. It combines documentary photography with a participatory action research methodology that is underpinned by the theoretical literature of education for critical consciousness, feminist theory and community-based approaches (211).

In particular are the perspectives of Brazilian educator Paulo Freire and his critique of society as being made up of dichotomous relationships which legitimize unequal, dominant and abusive forms of power by those who hold wealth and resources “oppressor”. The consequences that these forms of power have on “the oppressed” or those who suffer politically, financially and emotionally, can be challenged through the provision of literacy and educational programmes which empower people to “reflect” on their “actions” and thus becoming “recreators” of their own lives.

Oppression - overwhelming control - is necrophilia; it is nourished by love of death, not life. The banking concept of education, which serves the interests of oppression, is also necrophilia. Based on a mechanistic, static, naturalistic, spatialized view of consciousness, it transforms students into receiving objects. It attempts to control thinking and action, leads men to adjust to the world, and inhibits their creative power (212).
The Photovoice Method developed by Wang and colleagues follows an eight stage process (see Appendix 4.4 Photovoice Process). As a research approach it promotes a generic framework which should be adapted to the specific needs and strengths of the population groups being investigated. Broadly, Photovoice has three key aims: (1) to enable people to record and reflect their community's strengths and concerns; (2) to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs; and (3) to disseminate the results to policymakers (213).

An important feature of the Photovoice method is the technique of inductive questioning as developed by Wallerstein and Bernstein (1988) presented below in the mnemonic SHOWED:

1. (S) What do you See in this photograph?
2. (H) What is Happening in this photograph?
3. (O) How does this relate to Our lives?
4. (W) Why do these issues exist?
5. (E) How can we become empowered by our new social understanding?
6. (D) What can we do to address these issues? (214)

Participants are asked to discuss the photographs that they have produced, before the next photo assignment is set. As Lopez demonstrates in his work with Afro-American breast cancer patients, each photo assignment was analysed as an “iteration” (214) which can contribute towards an analysis and development framework about the participants’ experiences (Figure 4.8).
The next major stage of the project often involves the participants' photographs being displayed to policy makers (213).

### 4.4.2 Photovoice and ethnic communities in primary health services

Photovoice has been used to record the perspectives of minority ethnic communities. Several studies on the Latino communities in the United States have recorded the impacts of the exponential population growth of Hispanic communities since the 1990s and critical issues of adequate access to primary health services. Practitioners wanted to explore solutions around the cultural and language barriers associated to access (215). In one study, six expectant Latino mothers were asked to take photos to help identify strategies to improve service access and improve maternal health experiences. In a much larger study involving 60 community leaders and maternity patients, participants of an urban medical centre in the Contra Costa area of San Francisco produced photographic data about family, maternal and child health assets, and safe places for children's recreation. The improvement of the broader community environment within neighbourhoods was reflected as a key concern. Four Latino participants living with an intellectual disability revealed the importance of social relationships and cultural beliefs in God and traditional therapies to health (216).
Studies undertaken in ethnic communities are relevant to my two studies with Samoan families. The aim was to see the way in which disease and treatment are constructed in Samoan families and to see whether this might provide some useful insights that could be understood through participants' photographs.

4.4.3 Home setting

Perhaps much closer to the perimeters of my study of the indoor built environment, are the studies that were undertaken within the home setting. In the following set of articles, participants produced photographs of their lives with chronic health conditions, pain management and the stigmatisation with as cancer, HIV, disabilities and domestic violence. How the researchers dealt with participant recruitment and attrition rates was of interest to me, given the serious nature of my participants' circumstances.

One Photovoice study, used in conjunction with Quality of Life (QoL) surveys, explored the ways participants described a range of social supports built for them and their families (206). Photographs triangulated with other data sources to help illuminate the strategies participants developed to cope with HIV (217).

Insights about researchers dealing with chronic pain dynamics were highlighted in a study between Afro-American non-clinic based patients and clinic-based White/Caucasian patients (218). The low uptake for the White patients group was reflected in transport difficulties & physical health limitations and highlighted that the close follow-up of participants can reduce high attrition rates. This also included the length of duration between stages of a research project. A photograph of a knife (Photo4.2) was produced to describe pictorially one participant’s meaning of chronic pain.
My everyday pain feels like someone is stabbing me with a knife. The pain would stop for a bit and then I will get a surprise attack (of pain) again. Sometimes my pain is so bad that I feel like taking that sharp knife and chopping both hands off...and what is so disappointing is that there is not one pill that I have taken that has helped.

Photo 4.2 Chronic pain, like a knife

Interestingly, the health policies that encourage chronically unwell patients to pursue healthy lifestyles through exercise and leisure often do not take into account barriers such as high user fees at local recreational facilities, costs of transport and other financial affordability. Photographs of participants’ lives before diagnosis with HIV were often compared to their current lifestyles. Without adequate financial support from the state, participants were more likely to find ways to be self-reliant and access familial resources.

Spirituality was found to be an effective way of countering factors of social isolation and the stigma of racial prejudice. This was certainly the case for breast cancer survivors amongst rural Afro-American women who felt excluded from cancer support networks which were predominantly catered for white women (206) Lopez constructed the way African-American women positioned themselves within the community and provided support to others like them who lived with cancer. It highlighted the significance of spirituality underpinned by cultural beliefs.
Photo 4.3 Bible and spirituality

Photo 4.3 and 4.4 of the bible and the cemetery were important components of participants spiritual lives. In my investigation of Samoan culture, I was interested to see the extent to which spirituality and religion played a part in Samoan families’ lives.

Fourteen elderly women took photographs of resettling back at home after the hospital discharged them and were then interviewed six to eight weeks about their experiences. Results showed that hospital discharge plans were reductionist and deficient. The key issue identified in the study was that the discharge plans failed to correctly match patients’ ‘actual’ requirements at home. Discharge plans had incorporated very basic physical and medication needs which external caregiver
agents were paid service for fee to provide, rather than on the complex recovery and rehabilitation that the patient actually required at home (219).

The role of carers in my study was also an important component of home dialysis and home detention. Samoan families are often relied on to care for disabled and elderly patients; as well as providing sponsorship for detainees released into home imprisonment. The extent to which additional support from professional caregiver agencies is involved was also an area of interest in my study.

In a study interviewing fifteen parental dyads (a parent with a child with a disability), parents of children with disabilities took photos of important things about their life. The photographic data and interviews were matched with other studies on parents raising a child without a disability. The researchers found no significant differences in terms of family functioning variables of family and marital conflict, cohesion, and locus of control orientation. Both sets of parents shared common traits, however, the difficulties experienced in raising a child with disabilities was more intensified. Of the 313 photographs that were analysed, 50% were of family members and the majority were posed and not spontaneous. Data which yielded some of the richest information were those where photographs had not been taken. Another interesting finding which contrasts with studies in Hospital Settings (earlier section), was that there were very few pictures of special equipment. Researchers suggested the reason for this was that equipment used for care was not out of the ordinary, but integrated into everyday life (203).

Lastly, Photovoice has been used to investigate family domestic violence through the experiences of Mexican and Asian women. As participants, they were able to generate a co-operative and cohesive relationship of trust with the researchers with one another. An exhibition held at several public places, canvassed approximately 1000 viewers with the intention of shattering the stereotypes formulated about immigrant women as passive victims of machismo that were locked into traditional gender roles; presenting instead the multi-dimensionality of women’s lives.81 As in other studies carried out within ethnic communities, the women experienced barriers of racial discrimination when they tried to access regulatory services such as the

81 The article reported that there were four public exhibitions: a social service agency, the Mexican consulate, a cafe and a conference. One of the exhibitions was displayed for two months.
police, immigration and medical specialists for assistance. A photograph of an empty dinner table (Photo 4.5) represented for one participant the isolation she felt at home and the fear of preparing meals for her violent spouse. Photo 4.6 of the bathroom door represented a zone of safety for another participant when she had to use the locks to keep her husband out; the door was also a depressing reminder when he used a knife to pick at the locks (220).

![Photo 4.5 Empty dinner table](image1.png) ![Photo 4.6 Locked door](image2.png)

When I considered home detention for one of my case studies, I had wondered whether participants might discuss their crimes and the victims that they had hurt. Given the potential sensitivities involved this was an area that I would not enquire about unless it was first raised by the participants themselves.

### 4.4.4 Photovoice in New Zealand/Aotearoa

Photovoice was used in a unique project about Pacific young peoples’ experiences of extended family living. Two case groups involved interviews with young people living or having lived with grandparents. Photovoice was used with a case groups consisting of youth who were family members that had relocated into a purpose built residential state house in Porirua City in Wellington, Aotearoa/New Zealand. The newly-built house was a joint project involving Housing New Zealand with the Tokelauan community (Photo 4.7). It was designed with specific features, aimed to improve the health and well-being of the occupants of the extended family (221). In-depth interviews with the young people during the time they lived at their former state house provided comparative data of their experiences at the new house.
Crowding as key indicators of health was a theme that was explored in the Tokelauan house project in Wellington. The risks of infectious disease as well as the lack of privacy for occupants have been well documented as factors of crowding that impact many Pacific-extended families. Previously, the extended family of nine were housed in a three bedroom bungalow built by the state and typical of those that form the majority of the pre-1980s social housing stock in Aotearoa/New Zealand, constructed with lightweight timber materials and galvanised steel roof. Lacking insulation, the houses of this era are consequently extremely cold without any systematic heating. Findings of the Tokelau study revealed that the young people felt much healthier at the new house because it provided greater private space than the older house, was more energy efficient, generated lower energy consumption and had more open spaces for cultural opportunities and activities. It also allowed the extended family to build up cultural capital (Tokelauan language attrition and crafts making) and provided more structural space for familial hospitality in the care of elderly family members.

Finally, another interesting Photovoice project was on Pakeha women’s concurrent experiences of recovery and motherhood (222). Over a period of six weeks, Andrew conducted three sessions where participants learned about the Photovoice process and analysed the pictures they produced. The participant’s photographs had helped to define barriers within Pakeha culture that prevented them to access social networks and support organisations. A key finding of the study was the inherent “insular-ness” of Pakeha culture that engendered feelings of disconnection and “not
belonging-ness”. This in turn reinforced a sense of isolation which can be counterproductive to the recovery process and issues of access; highlighted is the relevance of support for recovery and living with mental illness.

One of the relevant findings in Andrew’s study was that Photovoice fails to provide specific guidelines for analysing the “participatory process” outside of that which centres on the presentation and dissemination of research findings to stakeholders (p.42). Andrew’s study with Pakeha women was one of the few that focused on expressions and characteristics of culture, or what may reasonably have been considered cultural or social capital.

As outlined, Photovoice has been effectively used to reveal diverse phenomena such as long-term chronic pain, private vs. public spaces, technological uptake and utilisation, all of which are relevant to issues covered in this thesis.

4.4.5 Hospital setting

Anglo-Australian heterosexual men reconstructed their experiences of radiation therapy for prostate cancer (Photo 4.8). Exposed to feelings of inadequacy and loss of dignity when disrobing for treatment (195), the participant photograph shown here was used to improve hospital training for radiation students.

![Photo 4.8 Loss of dignity.](image1)

![Photo 4.9 Doctor’s waiting room.](image2)

Understanding powerlessness through lived experiences is a key focus underpinning the Photovoice method (223). In Hussey’s research with five female to male transsexuals, the stress and on-going tensions of negotiating with public health care
and private insurance providers were highlighted. Using cameras to photograph public institutional spaces such as waiting rooms, doctors’ offices (Photo 4.9) and hospital medical equipment (below 4.10), participants data illuminated the subtle indiscretions about the incorrect use of gender pronoun “she” (instead of “he”) by professionals they interacted with. Word lists from interviews, as Freire had done in his literacy work in Brazil were used to produce key themes in relation to health providers’ professional competence about transsexual identity validation (212).

The study by Radley et al. investigated the physical setting of a hospital recovery ward with nine gastrointestinal patients admitted to and discharged from surgical and medical wards in a hospital located in the English Midlands (200). Participants were asked to photograph twelve significant things about their time in the ward and were interviewed twice about the photographs, pre-discharge and then at home. Underpinning the goals of the study was the theory that “recovery is a bodily act in response to shock the senses that hospitalization and surgery produce. Certain spaces and objects such as technology (drips, blood pressure machines) or personal facilities (bed, bathroom, toilet and curtains) gained significant meanings. Researchers attempted to understand and accept the way these meanings had been evoked from the photographs and the participants’ engagement with the ward at a sensory level. Technology in the ward was generally disliked, however, objects were associated with safety, security or threat dependent on how it tested or endorsed a participant’s dignity and comfort. Patient’s adherence or compliance showed how often they co-operated with technology and minimised the resistance towards the same objects and spaces thereby, motivating them to hasten their recovery time and discharge. In Photo 4.11, the notice board which was visible from the bed of one participant was the subject of interview at home when the patient was discharged. Post-operation, the patient had observed how the notice board took on animistic features and described how it had been “staring” at them and made them “smile”. In the ward, another participant made a photograph of the window in the ward (Photo 4.12). Their restricted mobility made them feel ambivalent of the hospital room “like a prison”. When the participant regained their mobility walking around the ward the same window is described as giving “hope”.
A key aspect of Photovoice is the participatory process that encourages collaboration between the researcher and the participants. The use of 'consensus' between the collaborators is recommended on decisions of the interpretation and coding of the photographic data.

One research team that consisted of mental health practitioners (six nurses and psychiatrists), utilised a rigorous process where transcripts were re-read by members of the team before the whole team came together to aggregate the themes of the study (201). Individual and collective team bias (or bracketing) could be openly challenged, particularly if researchers' had prior-knowledge of certain patients known
to the researchers. This was a way to monitor and check that the data’s validity and reliability was managed adequately.\textsuperscript{82}

\textbf{Figure 5. Eileen: She Substitutes Tattoos and Piercings for Past Cutting Behaviors.} This figure appears in color in the online version of the article. doi: 10.1111/j.1744-6163.2007.00143.x

Photo 4.13 A photo of a patient’s body piercing jewellery

Photo 4.13 was a photo taken by a participant whom was widely known by the research team. For the study, the researchers attempted to ensure that Photovoice could be an opportunity where ‘patients’ and not their physicians were asked to diagnose and give explanatory meaning to their illness experiences.

4.4.6 Urban Streets

In a study on homelessness, one researcher reported that during fieldwork he had reservations about training his participants in how to use disposable cameras because he was concerned he might cause them offense and embarrassment. In hindsight, he said that it would have been better to have done the training because it may have helped participants’ to produce better quality pictures and meanings about sleeping rough (224).

\textsuperscript{82} Team consisting of: 2 clinical nurse specialists, 1 psychologist, 1 psyche nurse in role of research intern, 1 psyche nurse practitioner student, 1 psychiatric nursing faculty member experienced in qualitative methods.
The accessibility of urban street paths, crossings and building entrances were featured in a study by senior citizens in English and French speaking regions of a Canadian city (194).

Photo 4.14 Heavy doors that is difficult to open when using a walker

Negotiating difficult building entrances (Photo 4.14) and dangerous street zones such as pedestrian crossings (Photo 4.15) were significant factors that dissuaded elderly people from commuting and walking. Participants’ photographs and the workshop themes created by all the participants working together were presented to city urban planners who felt inspired and stimulated to find practical solutions.

Photo 4.15 Barriers to walking
4.4.7 Summary of Photomethods and focus for this thesis

As outlined, Photovoice has been effectively used to reveal diverse phenomena such as long-term chronic pain, private vs. public spaces, technological uptake and utilisation, all of which are relevant to issues covered in this thesis. However, reviewing the studies of the use of Photovoice has highlighted that it is a research method; it is not an epistemological framework.

I was not able to find any articles of the use of Photomethods by Samoan communities to examine health and justice issues. For this reason, I began to reflect on the viability of constructing an epistemological framework where participant’s prior knowledge particularly with respect to the values and traditions of Samoan culture would assist in providing meaning about the indoor built environment, as discussed in Chapter 3. I was therefore interested to see how the photographs produced by participants of my study might compare to the images of the studies I reviewed.

Table 4.2 below summarises the main literature which resembled closest to different areas of my study and what I wanted to explore with Samoan families living with chronic illness and incarceration. In the furthest column, “Potential uses for my study) I have highlighted key points from each of the respective studies with the view that these could assist me in my study. Later in Chapter 7 Discussion (7.64) I revisit these studies and compare them to the findings of my two case studies.
Table 4.1: Literature Strengths and Weaknesses to My Study

<table>
<thead>
<tr>
<th>Author</th>
<th>Focus of investigation</th>
<th>Sample</th>
<th>Methods used</th>
<th>Potential uses for my study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baker &amp; Wang, et al.</td>
<td>psychosocial factors associated to chronic pain</td>
<td>Cohort of White clinic-based (? recruited; 0 completed) and African American non-clinic based patients (20 recruited; 13 completed); all aged 50 years and over.</td>
<td>Photovoice. Dedicated research assistant maintained close and ongoing contact with participants; transport/physical health limited, time between phases of study influenced participants' attendance to interviews and overall attrition rates.</td>
<td>Method close follow-up with outpatients of study influenced high uptake rates; Cohort comparison between two case groups</td>
</tr>
<tr>
<td>Castleden, H., T, et al.</td>
<td>part of a larger environmental project involving traditional lands</td>
<td>Huu-ay-aht First Nation 45 interviewed</td>
<td>Photovoice. ‘Pot luck dinners’ and home visits at elders home important in first 6 months for building rapport with participants</td>
<td>Networking with elders and focus on traditional maintenance of customs/lands</td>
</tr>
<tr>
<td>Frohmann, L. (2005)</td>
<td>experiences of battered women and the meaning of safety in their lives</td>
<td>3 women migrants groups: 2 Mexican (Spanish speaking); 1 South Asian (Uru &amp; Hindi speaking). 42 cameras distributed; 29 returned; 24 interviews; 26 involved in exhibits</td>
<td>Photo elicitation and grounded theory. Four public photo exhibitions. Translation of transcripts from Spanish to English; and English to Uru/Hindi.</td>
<td>Translation of ethnic languages; responding to violence; dissemination findings by public exhibitions</td>
</tr>
<tr>
<td>Gosselink, et al.</td>
<td>leisure behaviors of older women living in the United States and diagnosed with HIV/AIDS</td>
<td>4 older women diagnosed with HIV/AIDS; aged 50 to 56</td>
<td>QoL tool used with qualitative photo method. Participants asked to organise photos into themes and order significance to Bronfenbrenner's Ecological Model ‘self-satisfaction' with leisure/pre-leisure (life before and after HIV diagnosis)</td>
<td>Use of previously shot photos from participants’ past to understand present situations; small sample size comparable</td>
</tr>
<tr>
<td>Hodgetts, D., A, et al.</td>
<td>understanding of illness in circulation among participants and how they relate to survival on streets &amp; embodied deprivation</td>
<td>12 rough sleepers in London; 9 men 3 women; all white, British; aged 30-60 yrs; homeless from 1-27 years old.</td>
<td>Photovoice and Semi-structured interviews.</td>
<td>Housing and housed a central theme; spaces of health, care and violence explored</td>
</tr>
<tr>
<td>Lasseter, et al. (2007)</td>
<td>capture the everyday lives of parents raising a child with a disability</td>
<td>15 Parental dyads. 15 children, 20 male, 5 female; average age was 3½ yrs. Range of disabilities: Down Syndrome, developmental disabilities, of visual impairments, or speech disorders. Children's ethnicities were mostly non-Hispanic White (13), with 1 being Native American and 1 being Hispanic.</td>
<td>Interviews using photos - without formal structure. Content analysis.</td>
<td>Home-based important focus; dyads of parents and children considered; thematic analysis of photos carried out;</td>
</tr>
<tr>
<td>LeClerc, C. M., et al.</td>
<td>explore the everyday issues, challenges, struggles, and needs of elderly</td>
<td>29 recruited. 14 women aged 72-93 yrs agree to take part; 4 agree to take photographs; 10 interviewed without photos; 2 weeks for participants to take photos; research assistant maintained close contact; unstructured interviews; photo albums</td>
<td>Mismatch between hospital care plans and care provision at home; home-based care</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Population</td>
<td>Methods</td>
<td>Findings</td>
<td></td>
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<tr>
<td>-----------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Lockett, D. W., et al. (2005)</td>
<td>Community-dwelling women; 13 lived alone; 1 lived with spouse.</td>
<td>Identifying environmental to and facilitators to barriers of walking for seniors</td>
<td>Environmental safety, public hazards for elderly; disseminate findings to local authorities</td>
<td></td>
</tr>
<tr>
<td>Lopez, et al. (2005)</td>
<td>22 people living in Ottawa and Ontario, Canada; 18 women, 4 men involved in focus groups; 13 involved in taking photographs; average age 76; 26.3% had falls previous 12 months; walking most common activity. Two groups: French speaking, central city; 1 English speaking, inner-suburb; 1 English speaking from rural centre.</td>
<td>Photovoice; 3 Focus groups. Findings presented to town and city planners.</td>
<td>Issues of institutional racism and stigmatization; spirituality important for recovery</td>
<td></td>
</tr>
<tr>
<td>Oliffe, et al. (2007)</td>
<td>19 Anglo-Australian heterosexual men.</td>
<td>Photovoice, inductive data collection and photo elicitation. Numerous researcher-participant interactions &quot;pick ups&quot; and &quot;drop offs&quot; helped build rapport and fostered numerous informal observations. Anonymity important for participants who ensured people in their photos could not be identified.</td>
<td>Patient vulnerability using medical equipment at hospital; participants responses to diagnosis and preparation for death; explicit focus on mens' health</td>
<td></td>
</tr>
<tr>
<td>Perlstein, et al. (2003)</td>
<td>Six Hispanic women, over age 18; pregnant with first child; recently migrated.</td>
<td>Pilot programme, photo study; translation assistance.</td>
<td>Possible theme to look at: primary health service; language barriers and access issues</td>
<td></td>
</tr>
<tr>
<td>Radley, A., et al. (2003)</td>
<td>Gastrointestinal post-operation recovery in hospital ward; 9 participants; 5 women and 1 man; patients with gastrointestinal complaints; 1 week stay in hospital for surgery; 7 completed follow-up home interviews.</td>
<td>Photo elicitation. Two interviews phases: pre-discharge and post-discharge. Cameras distributed after surgery and photos taken while researcher present in the ward.</td>
<td>Photos taken at hospital &amp; follow-up interview at home</td>
<td></td>
</tr>
<tr>
<td>Singhal, A. et al. (2006)</td>
<td>8 children; 7 female community workers; first-time camera users. Amazon River area, Peru. Two research studies involving sketched drawings with children; and disposable cameras and photos with community workers.</td>
<td>Camera training provided. Two weeks given to shoot photos. 107 photos in data pool analysed. Narratives explaining photos recorded. Translation of transcripts from Spanish to English.</td>
<td>Mixed methods; evaluation of community programmes; gendered issues</td>
<td></td>
</tr>
</tbody>
</table>
4.5 Participant recruitment & inclusion criteria

4.5.1 Geographical location & number of participants

The target participant group for the two case studies were people aged over 16 years Samoan ethnicity who resided in the Wellington, Hutt Valley, Masterton, Levin, Wanganui or Palmerston North regions; with up to ten people in each group and key informants making up another sub-group where required.

4.5.2 Visual diary and family photographic albums

I was not able to find any articles of the use of Photomethods by Samoan communities to examine health and justice issues. For this reason, I began to reflect on the viability of constructing an epistemological framework where participant’s prior knowledge particularly with respect to the values and traditions of Samoan culture would assist in providing meaning about the indoor built environment, as discussed in Chapter 3. It was against this background when there were no previous studies of Samoan families which used either Photovoice or visual diaries using photographs\(^{83}\) to understand their experiences within the home setting, that I wanted to support

\(^{83}\) Appendix 4.3.1G the discussion of the historical use of visual diaries.
Samoan families to produce photographs for themselves and their families. This is important to my study because disposable cameras have been used previously to provide rich data. I produced a Visual Diary as a resource to assist the participants to understand what was involved in the study and to guide them in the production process (see Appendix 4.5.2) Later I compare the photographs produced by the participants of my study with the studies I reviewed.

4.5.3 Recruitment methods

There were two different recruitment processes used to enlist Samoan dialysis patients for the home dialysis Case Study. The first method involved a pamphlet being distributed by staff of the renal ward (Appendix 6.2). No participants were recruited by this method. One of the concerns that the renal clinician advisory member had about the recruitment of research participants by staff was that patients might feel that they were being ‘pressured’ to join the study at the renal ward. She also made helpful suggestions to the original Patients Dialysis Information Sheet saying that its length might put patients off from joining the study. I made a much smaller and less condensed pamphlet without a translation and this version was distributed by staff. It is unknown whether in fact this later pamphlet may have been insufficient information for people and whether this or other factors may have contributed to the lack of recruitment.

The second method involved me approaching individuals I knew through my community social networks who had had some treatment at the renal unit. Only one of the families that joined the study I knew fairly well. The others were known to me through work colleagues and these participants then referred others into the study. Through the snow ball technique into my community network I enlisted 12 participants (total n=12) (Appendix 6.3).

The recruitment of participants (detainees) for Case Study 2 (home detention) at a New Zealand prison was facilitated by a nominated senior prison officer who was authorised to screen for suitable candidates for the study (Appendix 6.4). As a result, three Samoan detainees joined the study and were interviewed at the prison. However, only two were interviewed at home detention stage of the study because
one of the participants withdrew. I decided not to recruit any more participants for the home detention study second stage because of limited time and resources.

Four additional interviews were conducted with key informants (four Pacific prison officers and one lawyer. This was important for collecting background information on Pacific offending and home detention.

During the second stage of collecting data are the mothers of the detainees (sponsor) agreed to join the study and be interviewed.

4.5.4 Participant inclusion criteria
Inclusion criteria was designed for participants of both case studies (see Appendix 6.5) Home dialysis patients and home detainees needed to be of Samoan descent and currently registered respectively with a district health board and corrections department. Carers and sponsors could include individuals who were not of Samoan ethnicity.

4.5.5 Participant exclusion criteria
One of the sample groups originally considered for interview were Taulasea (Traditional Healers) whom I interviewed for my Master’s thesis (23). After careful deliberation with my two supervisors, it was decided to exclude this group to focus exclusively on home dialysis patients and home detention detainees. The decision for this was the constraints of time to complete the field work and the composition of the groupings which already made it a complex and rich sample to work with. (Appendix 6.5)

4.5.6 Participant withdrawal
One of the participants emailed after release from prison to apologise that she wanted to withdraw from the study. She explained that being at home she wanted to move on with her life and this meant leaving the memory of prison behind her.

The two remaining participants continued on in the study. While one of them was fairly easy to contact by phone at her home, the other had to be contacted through CPS. Tracking down the detainee’s probation officer was also fairly straight forward;
the officer had been aware of my participant’s involvement in the study and was happy to organise a telephone conference for the following fortnight where I would be able to talk to with the participant directly. As planned the participant was at the CPS office while she was making routine probation visit to her probation officer, who I was then able to call and talked to. My participant had recently relocated to a new address. She told me that her sponsor (mother) was willing to be part of the study and that I could courier two cameras to them to take photographs of their experiences on home detention. I then organised a future date to visit for the second interview and asked for the cameras to be returned in the return envelope.

The follow-up with my other participant was to also organise the drop off of the camera and to set a date for the second interview. Her sponsor (mother) was unwilling to be involved in the study.

4.6 Information sheets about the studies and participant consent

4.6.1 Information sheets

Information sheets and consent forms for the study was designed for each of the case groups and translated from the English language into the Samoan language (Appendix 6.6 Summary of all the information sheets).

Home dialysis patients/carers (Appendices 7D1 to 7D4) and detainees/sponsors (Appendices 7D.5 to 7D.8) were given information sheets about the respective studies. These included the pamphlets (Appendix 7D.1) and summary sheets (Appendix 7D.6) that were distributed by renal staff and prison officers to generate interest amongst potential participants at the renal ward and prison institutions.

The information and consent forms that were translated into the Samoan language were checked by two members of my advisory group.84

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84 Appendices of Samoan language information and consent sheets: 7D.1, 7D.3, 7D.4, 7D.5, 7D.7, 7D.8, 7E.1, 7E.3, 7E.5 and 7E.6)
4.6.2 Consent forms

Four types of consent forms and their respective Samoan translations were designed for both studies. For the home dialysis study, a consent form for the patient and carer (Appendices 7E and 7E.1)

For the home detention study, a consent form was designed to firstly recruit the interest of a detainee at the prison institution to allow authorised correctional personnel to be able to contact me (Appendices 7E.2 and 7E.3). After a participant agreed to be part of the home detention study they were asked to sign the consent form (Appendices 7E.4 or 7E.5).

A separate consent form was designed for the participants to collect the signatures of people that they photographed for the study (Appendix 7E.6). Interestingly, none of the participants used these forms and so to protect the identities of those that were photographed I used photographic software to alter and conceal facial features. I informed participants during interviews that I would be taking this approach in relation to their photographs and there was general agreement for this to happen; nobody registered any opposition.

4.7 Field visits, cameras and in-depth interviews

4.7.1 Field visits - safety and hospitality

At the first points of contact with the participant (by telephone and in-person) I was able to ascertain fairly quickly whether there was interest to join the study. I also took the opportunity of building into the discussion that I would like to do a ‘hand-over’ of the camera and to give a brief description of what was involved in terms of producing their photographs (Appendix 7F).

In relation to the fieldwork visits, I prepared myself for any potential harm or discomfort that the participants might experience in relation to their circumstances. I was already aware that Samoan detainees were potentially more at risk because of the associated societal stigmatisation related to criminal offending. Similarly, dialysis patients and their families could be viewed as vulnerable citizens because they encounter stress and discomfort resulting from chronic kidney disease. Great care was being taken to ensure that adequate and appropriate written consent was
provided and collected. I expressed sincere appreciation of the participants' time taken to meet with me. I also reiterated that participants could withdraw from the study at any time.

Before visiting the homes of detainees, I notified the secretary of the Housing and Health Programme about the time and location of my interview. This was to ensure that my whereabouts was known at all times. I carried a portable cell-phone during field work at participants' homes in the event of an emergency, and if I needed to be contacted. The participants were also provided with my contact details and also my primary supervisor's in the event that they wished to discuss any matters related to the study; or if they felt unable or uncomfortable to discuss the matter with me. I was also reminded to be aware of trying not to differentially interact and be aware about how people were responding to me. The key locations of my study were two public institutional settings: the hospital renal ward, the state prison; and the participants' family homes. Because both these subject areas are new and that the literature search revealed very little information about either, I was hopeful that the collected data from the participants' photographs and face-to-face interviews would provide unique perspectives. Participants' vulnerability to factors such as depression, loss of appetite, tiredness and pain had to be taken into serious consideration as well, given the complex aspects associated with chronic kidney disease and imprisonment sentencing.

During the interview, I tried to assess whether the participant was willing to be involved in a later meeting with other participants of the study to discuss: 1) the 'public exhibition' of their photographs; and 2) the compilation of a selection of photographs to be reproduced for an 'educational resource' and 'family album' both which would be 'gifted' to the patients and families of the renal unit. A meeting was held in 2007 with nearly all of the participants and it was heartening to have had their support to ensure that the results of the home dialysis study were disseminated.

It was important for me to ensure that wherever possible I had to create for the participant, the greatest minimal physical effort and financial cost. Both the home dialysis and home detention participants faced potential complications with mobility issues. Home dialysis patients particularly may have found the demands of having to meet frequently too high on their physical wellbeing. Similarly, home detainees
would have needed to gain prior consent from their probation officer to be able to leave their home and attend research meetings. Having been aware of all of these potential difficulties for participants, I embarked instead on working with them in their home and selected to bear the costs of transport and gift of food through my research budget.

4.7.2 Cameras

Participants (except key informants) were given a resealable plastic bag that contained a Kodak (24 exposure) or Fuji (25 exposure) disposable camera. Each camera was labelled with an identifiable code. Inside the bag, participants were provided with a copy of the Guide Sheet (Appendix 7F Guide Sheet) and a consent form to participate in the study. Because most of the participants’ homes were within driving distance, I designed the Guide Sheet with Steps 1 to 5 as a way of assisting participants to produce their photographs in view of a ‘time’ schedule where I would be back to collect their cameras in order to develop the film and to return their photographs prior to the one-to-one in-depth interviews.

After gaining consent from the Department of Corrections for the detainees and the Hospital Renal Ward for the dialysis patients, I was able to distribute cameras to the participants to take photos of areas of institutional life like the prison cells and renal dialysis units. The participants were also asked to include their home environments as places where they might want to make photographs of their day-to-day life. I worked closely with my two doctoral supervisors who provided continuous feedback about the data I collected from the participants.

I chose not to bring the participants of my two respective case studies together for camera training or for the exploration or “posing” of possible themes. Instead, I held individual face-to-face discussions with each participant at their home and showed them the Visual Diary (refer above 4.5.2) that I produced as a way of helping them to comprehend the main objectives of the study and to view the examples of a range of photographs that were possible to produce.

I did it this way largely because I was not sure if participants had the time, resources or the inclination to meet with other participants. Like Castleden and colleagues, I
favoured a process of “building trust” (202), particularly the elderly leaders whom I already had a previous relationship with through my community. I was also uncertain whether they would be willing to attend meetings on more than one occasion.

I was able to distribute the cameras in person and collect them again at a later date after the participants had produced their photographs. I used a postal courier service to deliver cameras to two families that lived outside of the Wellington region. Inside the courier packages, I enclosed pre-paid courier bags so that the participants could mail their cameras back to my office so that the film could be developed (see Appendix 7F.1). I left it completely up to the participants of each household whether they wanted to work with other family members.

Additional cameras were used for the study and these were cameras that I carried with me on field visits while making the visual diary, visiting participants who were at the renal unit and prison institutions. I also ensured that I had a spare camera in the car wherever I visited the participants in the event that they requested a camera replacement, or if I needed to use one during an interview.

4.7.3 In-depth interview and open-ended questions

In-depth interviews were conducted with participants of both case studies. After discussion with my supervisors, I made the decision to interview each participant on their own rather than in pairs or as a family group, even though it was possible, because family members were often at home at the same time. Interviewing a participant on their own, would also allow me time to explore at a greater depth, if I needed to, topics that had not been raised in the study previously by other participants or an issue which might not have been easy for another member of the family to talk about. It was also a time where I could triangulate and compare themes shared across all the participant groups. It was important that participants felt that they had their own autonomy to produce the kinds of photographs they wanted and for them to be able to express themselves freely. After informing participants that I wished to interview them alone, I also told them that if they wanted later to be interviewed with other family members I was happy to do so.
Baker and Wang highlighted the real difficulties for patients with chronic pain in getting themselves to a research meeting with other participants. The participants' health condition (chronic pain) was in part a barrier to being able to participate in the researcher’s Photovoice study and consequently contributed to a low attrition rate for that specific sample group (218). Without being sure about my participants' wellbeing or their available resources, I was unwilling to presume that they would be either ‘capable’ or ‘willing’ to attend this innovative yet relatively demanding research process.

Set out below are prompts used in the interviews with participants. (See Appendix 7G for fuller list of questions).

**General Questions and Themes about Home & Living Arrangements**

- Features of home they liked
- Experience of the home services they received
- Description in their own words what it’s like to have to stay in their home
- Equipment installed in house
- How they felt when people came to their home and saw the installed equipment
- Questions about Samoan cultural rituals and expressions related to justice, health and home
- Household occupancy, size of property, how long they have lived in the house, sketch of the layout of the house
- Features of the property that are important to health, wellbeing and healing
- Aspects of the house that inhibit or restricts them in some way
- Description of the ‘ideal house’
- Any alagaupu (proverbial sayings), bible verse or ‘saying’ that describes their experience of living in home detention/home dialysis
- Kinds of activities or programmes they are involved with
- Any outside services they are involved with. How often did they access them?

**Questions about Photographs & Use of Cameras**

- Tell me about your photographs.
- What was it like to use a camera to tell your story?
- Was there enough time given to take your photos?
- Was the Visual Diary useful?
Recommendations for the Study (Participants & Key Informants)

- What recommendations would you make to the hospital/prison?
- How do you think the study could assist others with similar experiences?
- What would you like to see in the future?

4.7.4  Interviewing about the visual data

Using the photographs as the focus for the in-depth interviews enabled people to reflect on the experience of undertaking home dialysis, imprisonment and home detention (Appendix 7G). The participants’ production of photographic images and their subsequent narratives revealed the place and importance of home and institutional impacts on the phenomena of their day-to-day interactions.

I asked the participants to reflect on the photograph they had taken. The methodological process of interviews and photographic production generated rich and relevant fields and categories for analysis. As can be seen below, participants’ descriptions about the material content of their photographs are referenced to historical events, objects and people. These are detailed with physical dimensions, proximity, character, colour, feelings and emotions that have tactile and meaningful representation and expression. For example, the photographs helped the participants remember before and after they were in prison. They also referred to the photographs in expressions such as:

a) “Before I came into prison…,” <=> “…after I was released into home detention…”; and
b) “When I took this photograph…,” <=> “…looking at this picture of…”

The participants were encouraged to utilise the photographs in whichever way they wanted. Often participants alternated between describing what they did to “produce” one or several clusters of photographs, as well as providing the “rationale” behind its production. Embedded in their intuition and conceptualisation of the production process, their reflection on the photograph’s material content, through viewing the photograph the participant shared their experiences about chronic illness and incarceration:
1. recollecting the steps taken to produce the photograph
2. recollecting the prompts to take the photograph
3. commenting on a specific feature within the photograph, its relevance and associated meanings
4. making an evaluative statement in relation to a relevant question or issue which the photograph highlights, minimises or adequately represents.

In the two case studies, some participants constructed photographs that consisted of or resembled the same content that were produced by others within their family. While the sample group was purposely selected for its homogeneity (Samoan individuals who experience home dialysis and home detention); the differences between the sub-groups within and across all families are significantly diverse.

During the interview, I tried to maintain as much fluidity as possible by following the participant's lead on the order and preference of the photographs they wanted to talk about. Four elderly participants in the dialysis study, who took photographs, waited until the end of the interview to discuss their photographs, using the majority of the interview to talk about family matters and the previous years before they or their spouse contracted CKD. Whenever they referred to the photo album, I took it as a cue that they were finally ready to talk about their photographs, at which stage, I tried to encourage them to explore whether there was one or several levels of 'internal' and 'external' meanings of their photographs.

Interestingly, none of the participants asked for a family group interview. This might have been because they felt that at the time their individual interview was sufficient. On the other hand, in consideration of the amount of time and effort that it took participants to produce photographs (two and for some up to eight weeks); the extra interview might have been too physically or even emotionally challenging. I say this because at various stages of taking their photographs, some participants told me that they were very emotional and tearful; others found it physically exhausting. The reasons participants reported, differed according to their circumstances, however, the importance of the one-to-one interview offered the opportunity for them to reflect deeply about the range of triggers and responses they had in relation to issues about their illness or being confined at home or having lost their mobility and freedom. For some participants, ‘thinking about’ the differences between ‘home’ and ‘institutional
services’ such as the hospital and prison or about an official like a doctor or a prison officer provided other insights about their lived experiences on home dialysis and home detention. Participants shared openly how they felt about actual using the cameras to record their experiences, describing both the positive and negative aspects of the production process.

Only a few participants enquired about the photographs that other participants had produced, including those from within their own family and other families in the study. Some said that they were generally very curious to ‘see’ what others had done with their cameras and whether there were ‘similarities’ and ‘differences’ with the photos they produced.

4.8 Coding and data analysis

4.8.1 Coding

Prior to distributing, codes were assigned to each camera. Coding of dialysis cameras was suffixed with ‘dy’ plus the camera number, e.g. dy 1. Detention cameras were suffixed with ‘dt’ plus the camera number. In households where there were more than one cameras distributed, the initials of the participant’s name was labelled alongside the camera code number so that participants could more easily recognise which camera belonged to them. When the film rolls for each camera were taken for development at a local photographic supplier, the researcher asked the supplier to transfer the bright yellow sticky coded label from the camera onto the corresponding envelope that the photo prints were packaged in. This made handling several film prints easier to identify per participant. With each set of prints, the photo supplier provided a glossy window serial card of all the photos in the set. This window card was then coded to the corresponding camera code number and filed together with compact disk and cellophane negative film strips, into the researcher’s master photo album, which were also labelled with the same corresponding code. The master photo album was the researcher’s record of all the original film and photo print sets.

Codes and job number were allocated to each participant digital recorded interview with suffix DSS2200, plus the number followed by a job number, e.g. DSS2200890
Job 336. This code was transferred to the written transcripts produced for each interview.

4.8.2 Data collation

The data included a collection of photographs, film proofs and negatives, digital recordings and interview transcripts that depicted the life experiences of the participants. The researcher provided all the participants with a complete set of photos produced from their assigned disposable cameras. The photo prints (6X4 size matted paper) were taken and placed inside a photo album and dropped off (or courier posted) to the participant three to seven days prior to the recorded interview.

After the recorded interview, the data were coded using computer software NVivo 6 to determine textual themes of all interviews. Photographs were digitally organised, sorted and indexed into themes using Picasa 2 and Microsoft Office Picture Manager. Adobe Image Ready C.S Version 8 and Picasa 3 was used to edit photo images to disguise human faces, objects and locations that could give away the identity of participants.

After this first layer of analysis was carried out, a maximum of 19 themes and 98 sub-categories were produced.

4.8.3 Data analysis of photographs & audio transcriptions

A total of 632 photographs for the study were produced by participants of the two case study groups. Participants of the home dialysis study produced 542 images and participants of the home detention study produced 90 photographs.

The audio transcripts of the key informant interviews were organised and categorised using Nvivo software and the photographs on Picasa software. Switching between the two different source materials of photograph and transcript was an involved and lengthy process. As much as possible I tried to pay attention to the “internal narrative” through the question: “What is this picture of?” As well as focussing on the “external narrative” by asking: “Who, why and when was this picture taken?” (199).
The meanings and descriptions about a photograph that related to an aspect of a family’s social interactions inside and outside the home were analysed using the participants’ audio transcripts and photographic images. Analysing the photographic and textual data was sometimes easier to do when participants had talked specifically about a photograph or a group of photographs.

When I decided to do a nominal count of the themes and categories of all the ‘dialysis participant’s’ photographs, I discovered that the systematic appraisal of a photograph was not always straightforward. When participants used several descriptions about one or several photographs the descriptions were checked and rechecked.

Conversely a participant sometimes made no comment about a photograph that they produced. In such cases, I assessed the photograph deductively and explored the presence and absence of various themes. Consideration was also given as to how photographs were produced sequentially, or how the subject matter might be inferred by other surrounding photographs. However, in these circumstances, I decided that if the participant had not talked about an object (for example the refrigerator), then I did not attribute a count or categorise it to “appliances”. A count would only be given to a photograph or photographs, if the participant had articulated a description or meaning to it.

The decision not to do a nominal frequency count of the home detention photographs was deliberate. I wanted to emphasise the themes produced from the participants’ transcripts, as opposed to aggregating the themes for all the participants. Also, in comparison to the higher number of participants in the dialysis case study, and the much more extensive collection of photographs that were produced, the home detention group had fewer participants and also considerably fewer images.

Attention as to ‘how’ a participant described the process of producing a photograph was also taken into account and this sometimes could not be separated from the description that they attributed to the content or topic of a photograph. The references about ‘production’ were also very useful because participants provided ‘rich’ and ‘deep ‘meanings’ of home, family, wellbeing and other subjects as they
simultaneously expressed, translated, interpreted and defined what these experiences were.

This often resulted in participants using descriptions about their visceral senses such as ‘smell’, ‘taste’, ‘sound’ and ‘touch’. Pink highlights the importance of the ‘sensory context’ from which visual data are produced:85 “I aim to understand which sensory categories and metaphors they used and why. I cannot reproduce the tapes here, but I use transcripts and description to evoke something of this research context” (p. 61)(192).

Researchers, she argues, should go further than merely describing what is “seen” in a photograph and should report on the other “material manifestations of the sensory home” (p. 62) (192). “Much of the knowledge produced through these encounters was represented visually. To attempt to translate it into words reduce its quality as knowledge and redefine the type of experience being represented” (p. 63) (192).

In keeping with Pink’s recommendation to analyse data into sensory categories, I read the transcripts closely, as did my first supervisor. We read the transcripts independently and then discussed the emerging themes and representational meanings. The categories used to assess the photographs were often from participants’ responses to or in relation with phenomena of their day-to-day experiences, activities, involvements to and against other living beings (people and animals) and inanimate objects (electrical appliances, furniture and medical consumables). Thematic analysis was informed by Samoan epistemology (Chapter 3) particularly in relation to participants’ roles and responsibilities within the front, middle and back of house. Initially, I counted and identified the themes in dialysis study which had more participants and a higher number of photographs. As a result, 11 key themes emerged:

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85 Pink video recorded her participants, as opposed to the way that my participants used cameras to produce their own images. However, what she says about the translation of visual data is an important departure from the “traditional ethnographic” approach in anthropology which has tended to ignore the senses.
1. access barrier
2. building renovation
3. family activity
4. family medical routine
5. family medical waste
6. photo of loved one
7. photograph of a photograph
8. family house
9. public place
10. special objects
11. open spaces.

As I had fewer participants in the home detention case study, I did not do this step (see Results Chapters 5 and 6; Appendix 9 and 10 Additional Notes on participant interviews).

4.8.4 Digital Audio Recorder

An in-depth interview with each participant was recorded using an Olympus Digital Recorder DSS22000. The interview was downloaded onto computer as a WMA sound file and stored for transcription in the DSS Transcription Module File. Back up copies of all recordings were made to a USP memory device and an MP3 memory device and stored separately in a locked filing cabinet.

4.9 University Ethical Approval

In mid-2005, I submitted to applications for ethical and funding approval to the two key educational and funder organisations that supported my doctoral study. Initially, five key components of the study had been identified: home detention, home dialysis, Samoan taulasea (traditional healers), cultural supervision, photographic methodology. Ethics approval from Otago University involving human participants (Category B) was secured in August 2005 and June 2007. The later application (June 2007) was submitted to amend the participant criteria of the detainee group from 18 to 16 years of age, and to extend the gender criteria to include Samoan males which in the earlier application was limited to Samoan females.

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86 University of Otago Ethics Committee and the New Zealand Health Research Council.
4.9.1 Ethics for Dialysis Study

No special ethical approval was sought or request from the Capital and Coast District Health Board to carry out research with the 12 Samoan dialysis patients and their carers. Unlike the family members in the home detention case study, where the main ‘carer’ known as a ‘sponsor’ is required to undergo rigorous screening for suitability for home detention, the arrangements between the public health services and the respective patient and their carer are less formally recognised.

4.9.2 Ethics Approval from the Ministry of Justice

Also in July 2005, after discussions with the Manager of a New Zealand woman’s prison, I was provided provisional consent to carry out research with female detainee (Appendix 7H). This consent also allowed me to conduct interviews with prison officers on site at the prison. I was given co-operation and support through authorised staff selected by the Manager to have prisoners screened according to the ‘inclusion and exclusion criteria’ set for the home detention study. In 2006, I was granted provisional permission to take a disposable camera into the prison so that a participant (detainee) could take photographs of their cell for the purposes of the study. In May 2007, I was given full ethical approval from the Ministry of Justice and Department of Corrections to carry out my study under the formal contractual obligations as an ‘external researcher’ (Appendix 7I).

4.10 Dissemination of findings

An important component of Photovoice is the dissemination of the research findings that could make service or policy improvements for those who participated in the study. Throughout the course of the PhD investigation I have made serious and continued contact with the participants of both case studies to update them of the progress made to disseminate the findings back to their respective public health and corrections authorities. The results sections for case studies which are presented in Chapters Five and Six, describe how the findings were disseminated. Appendix 7K also provides a list of conference presentations and meetings I had where the findings of both case studies were presented. (Also Dissemination in the results chapters 5.2.10.4 (dialysis case study) and 6.2.6 (home detention case study) and discussion in 7.2.5.4.)
5 RESULTS – HOME DIALYSIS CASE STUDY

5.1 Organisation of Home Dialysis Results

Housing is an important aspect of human life and wellbeing, and a place where Samoan families integrate public services into their day-to-day lives within the privacy of their homes. An important question that was identified from the earlier chapters was Samoan families’ capacity to manage the complex formal arrangements associated with home dialysis alongside their familial and cultural responsibilities. This chapter presents the results of the Home Dialysis Case Study and is divided into six main sections.

5.1.1 Key themes and headings

As a way of contextualising participants’ home-based formal obligations associated with State institutional services, I have organised the themes of the participant’s photographs and interviews into Table 5 below according to the three domains of the traditional Samoan dwelling: the front of house (Section A) describes the experiences of the dialysis families within the institutional setting and where the state is implicitly involved with the families through its services at home; the back of house focuses on the families day-to-day activities (Section B); the middle of house draws together the protective mechanisms associated to the families’ cultural and social practices and traditions (Section C). The results chapter ends with a focus on major challenges that families encounter and what they view as areas of service improvement that could be made. Table 5 (below) is a summary of the key themes.
### Table 5-1: Section A – Front of House
The Institutional Setting of Home Dialysis

<table>
<thead>
<tr>
<th>5.3.1</th>
<th>District Health Board Policy of Patient Empowerment</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.3.1</td>
<td>The hospital – a “better place than home”</td>
</tr>
<tr>
<td>5.3.2</td>
<td>The hospital built environment – a “second home”</td>
</tr>
<tr>
<td>5.3.3</td>
<td>Lack of information within the hospital setting</td>
</tr>
<tr>
<td>5.3.4</td>
<td>The institution of “able” and “unable”</td>
</tr>
<tr>
<td>5.3.5</td>
<td>Weak primary health care links to the renal unit</td>
</tr>
<tr>
<td>5.3.6</td>
<td>Young people feeling out of place</td>
</tr>
<tr>
<td>5.3.7</td>
<td>Summary</td>
</tr>
</tbody>
</table>

### Table 5-2: Section B – Back of House
Adapting the Family Home for Dialysis

<table>
<thead>
<tr>
<th>5.4.1</th>
<th>HNZC renovation and a large electricity bill</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.4.2</td>
<td>Bigger house, colder house, bigger electricity bills</td>
</tr>
<tr>
<td>5.4.3</td>
<td>Space, sterility and technique</td>
</tr>
<tr>
<td>5.4.4</td>
<td>Independence on home dialysis</td>
</tr>
<tr>
<td>5.4.5</td>
<td>Two separate places</td>
</tr>
<tr>
<td>5.4.6</td>
<td>Transition from peritoneal dialysis to palliative care</td>
</tr>
<tr>
<td>5.4.7</td>
<td>Waste Disposal</td>
</tr>
<tr>
<td>5.4.8</td>
<td>Extra laundry and water use</td>
</tr>
<tr>
<td>5.4.9</td>
<td>Electrical appliances</td>
</tr>
<tr>
<td>5.4.9.1</td>
<td>Fear of household electrical appliances</td>
</tr>
<tr>
<td>5.4.9.2</td>
<td>Microwave</td>
</tr>
<tr>
<td>5.4.10</td>
<td>Cold house even with insulation</td>
</tr>
<tr>
<td>5.4.11</td>
<td>Summary</td>
</tr>
</tbody>
</table>
### Table 5-3: Section C – Middle of House

**House of Healing, House of Ashes: The Middle of the House for Home Dialysis**

<table>
<thead>
<tr>
<th>Section C – Middle of House</th>
<th>House of Healing, House of Ashes: The Middle of the House for Home Dialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.5 Va tapuia &amp; Samoan spirituality in the dialysis household</td>
<td></td>
</tr>
<tr>
<td>5.5.1 The shedding house</td>
<td></td>
</tr>
<tr>
<td>5.5.1.1 Mirrors connect the waking and sleeping worlds</td>
<td></td>
</tr>
<tr>
<td>5.5.1.2 Clocks for connecting the present, past and future</td>
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<tr>
<td>5.5.1.3 The important role of church social networks</td>
<td></td>
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<tr>
<td>5.5.1.4 Misunderstanding SKD and the curse of dialysis</td>
<td></td>
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<tr>
<td>5.5.2 The major role of family members within the home dialysis built environment</td>
<td></td>
</tr>
<tr>
<td>5.5.2.1 The vital assistance of children to their siblings</td>
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<tr>
<td>5.5.2.2 Seeing and valuing the same things</td>
<td></td>
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<tr>
<td>5.5.2.3 Agreeing to modify traditional gendered arrangements</td>
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<tr>
<td>5.5.3 Samoan culture and identity</td>
<td></td>
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<tr>
<td>5.5.3.1 The important role of Tatau/tatoo in Samoan masculinity</td>
<td></td>
</tr>
<tr>
<td>5.5.3.2 Mixed Samoan heritage</td>
<td></td>
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<tr>
<td>5.5.3.3 Samoan traditional healers</td>
<td></td>
</tr>
<tr>
<td>5.5.3.4 Barriers to kidney transplantation or Tautua toto</td>
<td></td>
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<tr>
<td>5.5.3.5 Summary</td>
<td></td>
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</tbody>
</table>

### Table 5-4: Section D - The Major Challenges Of Home Dialysis

<table>
<thead>
<tr>
<th>Section D - The Major Challenges Of Home Dialysis</th>
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</thead>
<tbody>
<tr>
<td>5.6 Compliance and conditions</td>
</tr>
<tr>
<td>5.6.1 Nutrition and diet</td>
</tr>
<tr>
<td>5.6.2 Giving up alcohol and leisure activities</td>
</tr>
<tr>
<td>5.6.3 Relinquishing autonomy of the carer to external agencies</td>
</tr>
<tr>
<td>5.7 Isolation at home</td>
</tr>
<tr>
<td>5.7.1 Without spousal support</td>
</tr>
<tr>
<td>5.7.2 Challenges of mobility and transport to hospital</td>
</tr>
<tr>
<td>5.7.3.1 Dialysis training for carers</td>
</tr>
<tr>
<td>5.7.3.2 Home visits and clinical support in the home</td>
</tr>
<tr>
<td>5.7.3.3 Support to employment</td>
</tr>
<tr>
<td>5.7.3.4 Translating medical information for Pacific families</td>
</tr>
<tr>
<td>5.7.4 Summary</td>
</tr>
</tbody>
</table>

### 5.2 Home dialysis participants’ demographic information

The qualitative component of this study investigated the perspectives of twelve participants (n=12) of five Samoan families’ living in the Wellington, Hutt Valley, Porirua and Kapiti areas. A patient from each family in the study was registered at the Capital Coast & District Health Board (CCDHB) Renal Services. Following diagnoses of ESRF (end-stage renal failure) renal dialysis and kidney transplantation was recommended to maintain life.
Sadly, over the duration of the study, two elderly participants (Ata and Olo) passed away a short time after I interviewed them (2007 and 2008); and then a third, Ie (the youngest patient) passed away earlier this year (2012). The approval process for using the interviews is discussed in the Ethics section.

5.2.1 Families in the study

Five families consisting of 13 participants (6 male and 7 female) were involved in the dialysis study. A patient from each family was identified (n=5). There were more carers (n=8) than patients (n=5).

5.2.2 Home dialysis patients ages

The two eldest patients were Ata (72), Olī and Efū (67). Olī passed away before she could be interviewed. Uso and Ie were the youngest patients respectively aged 22 and 23 years old.

5.2.3 Home dialysis carers

There were more female carers (n=5) than male carers (n=3). The age of the oldest carer, Olo was 72, (male); and the youngest, Ufi was aged 18 (female). The two oldest carers (Olo and Emo) were also the two eldest spouses.

Only three out of eight of the carers were living in the same house as the dialysis patient at the time of interview. Two patient-parent dyads (Ie (patient/daughter) with Ivi (mother/carer); Uso (son/patient). Uga and Usu (mother and father carers).

5.2.4 Ethnicity

All the participants (n=11), except two were of Samoan descent; of whom seven were born in Aotearoa (Ie, Ivi, Ofe, Osi, Uso, Usu and Ufi). The eldest participants in the study were born in Samoa and migrated to Aotearoa in the 1950s (Ata), 1960s (Olī, Olo) and 1990s (Efū, Emo). Ivi and Uga (both carers) were two non-Samoan participants in the study whose ethnicities respectively were European Kiwi/Scottish (Uga) and Cook Islands Māori (Ivi).
5.2.5 Self-reported cause of chronic kidney disease

Participants identified the following health conditions as a contributory factor of chronic kidney disease: hypertension, kidney stones, chronic reflux nephropathy, diabetes and nephritis.

5.2.6 Patient treatment modes

In the last 12 months (prior to being interviewed), four out of five of the patients undertook the conventional haemodialysis schedule of four to five hours, every two days (Ata, Efu, Ie and Uso). Uso and le both dialysed at home on a dialysis machine but Ie switched to hospital dialysis after 6 months. Ata was the only patient not to have taken up home dialysis.

Of all the patients in the study, Ie had the most years on dialysis and she was the youngest patient. Ie had dialysed for 11 years (mostly on Continual Ambulatory Peritoneal Dialysis or CAPD before switching to haemodialysis); compared to Ata (2 years), Efu (3 years) and Uso (1 year). There was only one other patient that spent the same number of years on dialysis as Ie, and that was Olī (deceased member of Family 4) who utilised CAPD. 88

5.2.7 Employment

At the time of the study, only two patients were in paid (part-time) employment (Uso and Ie). The other two remaining patients (Ata, Efu) were retired senior citizens. Five carers (Emo, Ivi, Olo, Ofe, Uga) said they had given up paid employment over some 6 months to be at home to assist the patient. At the time of interview, Ivi, Uga, Osi and Ofe returned to paid employment and continued with their carer roles at home. Emo was unable to work because of her chronic health, but she earned a little income from a hobby she did from home.

5.2.8 Decisions in relation to the death of a family member

Four of the five families reported that they had discussed plans in relation to last wishes, funeral arrangements, interment and burial. Olo and his children (Ofe and

88 Olī died 12 months before her family became involved in the study.
Osi) (Family 4) provided palliative care at home for their family member until the end of life. Concerns around the maintenance of life were also raised when family members explored transplantation or whenever the patient was very sick.

5.2.9 Housing tenure of the home dialysis participants

An important issue for this thesis is how wellbeing is understood through a person’s lived experiences of housing while undergoing home dialysis and home detention. In this thesis, ‘home’ and ‘house’ are therefore examined as physical and symbolic expressions of the dichotomies that exist predominantly within the home setting. In this section, I summarise the housing tenure of the participants in both studies, the effects of housing maintenance and the suitability of houses for home-based public services.

As with Samoan households overall in New Zealand, most of the households in my two case studies lived in rented accommodation. Four of the seven households rented properties from the state housing sector (HNZC, Housing New Zealand Corporation) and the remaining three households were living in homes that they owned, which was much lower than the national average for Pacific home owners (62).

Three of five families of the dialysis study (Families 1, 2 and 3) were tenants of Housing New Zealand Corporation (HCNZ). They lived in stand-alone houses in three different geographical locations: Wellington Central, Porirua City and the Hutt Valley City. Efu and Ie’s families were prioritised for housing with HNZC because of CKD.

Ata’s (aged 72 years old) life-long tenancy with HNZC spanned 50 years. He raised a large family of eight as a migrant of the early 1950’s Pacific Diasporas in the same house. Home dialysis would have been ideal, because he had a spare bedroom and ample space for supplies and a haemodialysis machine. What he did not have was someone who could assist him at home with his treatments. A major concern for him in relation to the home haemodialysis machine was the potential interference that electrical appliances, could have on his heart-pace-maker.
Efū (aged 67) and Emo migrated in the ‘70s to be with their children who moved here for work. Because of his chronic kidney disease, Efū was given a HNZC property that was already modified for a person with limited mobility. One room in their three-bedroom house was dedicated to dialysis treatment and storage of dialysis disposables.

Ivi had a tragic story of moving her family of eight from one terrible rental to another; and this finally changed when a HNZC case manager reprioritised them for a state house. After inspecting their private rental property, the case manager was shocked to see the cramped, mouldy and crowded conditions. Ie, the eldest daughter, had been dialysing at home from the age of 11, and when she joined the study, she was 20. For a decade, the family moved from bad rental to another; Ie’s numerous boxes of dialysis supplies could never be stored properly because there was never enough room. Without the help of the state for a larger property, the family would have continued renting poor quality private rentals, based on what they could afford.

Notwithstanding the delays that Ivi encountered when she was wait-listed with HNZC for a large property, the participants of the study were prioritised into social housing for home dialysis and home detention, which indicates at the time, the largely progressive and functional operations of HNZC’s social assessments.

Three households in the study lived in family-owned homes. Uso a young dialysis patient was flatting with friends at the time when he was diagnosed with CKD. His parents offered a refurbished room at the family home, so he could have a separate space to do his dialysis and this enabled him to continue living at his flat. His parents felt it was important for Uso to be able to maintain his independence as a young adult. As this family owned their own home, they had the means to support their son in being independent while maintaining extended family support.

Olo and his wife Olī bought their 1930s house in the early 1950s. A local Māori provider carried out an insulation retrofitting of the floor and ceilings about a year before they became involved in the study. The family used the dining/kitchen and a spare bedroom to store the dialysis supplies, as well as the laundry and back shed to stack the used dialysate bags which were disposed of with the rest of the household rubbish.
### Table 5-5: Summary of participants’ demographic information

<table>
<thead>
<tr>
<th>Family Groups Dialysis</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>family members</td>
<td>Ata</td>
<td>Efū</td>
<td>Emo</td>
<td>Ie</td>
<td>Ivi</td>
</tr>
<tr>
<td>ethnicity Samoa</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>place of birth</td>
<td>Samoa</td>
<td>Samoa</td>
<td>Samoa</td>
<td>NZ</td>
<td>NZ</td>
</tr>
<tr>
<td>gender (female)</td>
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<td></td>
<td></td>
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<tr>
<td>gender (male)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>length of dialysis treatment at time of interview (years)</td>
<td>2</td>
<td>3</td>
<td>8</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>Patient</td>
<td></td>
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<tr>
<td>Carer</td>
<td></td>
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</tr>
<tr>
<td>Spouse (in relation to patient)</td>
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<td></td>
</tr>
<tr>
<td>Father</td>
<td></td>
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<tr>
<td>Mother</td>
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<td></td>
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<tr>
<td>Son</td>
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<tr>
<td>Daughter</td>
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<td></td>
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<tr>
<td>Sister</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>72</td>
<td>67</td>
<td>63</td>
<td>22</td>
<td>41</td>
</tr>
<tr>
<td>type of house</td>
<td>HNZC</td>
<td>HNZC</td>
<td>HNZC</td>
<td>Family Owned</td>
<td>Family Owned</td>
</tr>
<tr>
<td>maximum occupants in the household</td>
<td>3</td>
<td>3</td>
<td>8</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
5.2.10.1 Cameras

Thirteen disposable cameras were distributed and taken up by 10 participants. One participant chose not to use the disposable camera in preference for the quality produced using their own personal digital camera (Uso, patient, Family 5). In addition, both Uso and Ofe asked if they could submit photographs they produced prior to joining the study. The researcher agreed because the photographs represented for the participants an aspect of their experience of living with dialysis. Only one participant made the decision not to take any photographs, because he felt that the photos submitted by two other members of his family would be sufficient (Olo, carer, Family 3).  

5.2.10.2 Participant Photographic Sets

In total 300 photographs were produced for the home dialysis study. In Table 7.1, photographs are arranged by two sets. The first set of photographs was produced with the disposable camera that I distributed. The second set of photographs was produced by the participant with their own digital cameras.

The participant who produced the most photographs was Ofe (carer, n=89, Family 4). Usu (carer, Family 5) produced the least number (n=5).

Individuals of the same family produced similar photographs, without being aware of what the other was doing. For example, Ivi and Ie (mother and daughter) produced similar photos of their work stations in their workplaces. Ofe and Osi’s (sister and brother) photographs of the same microwave, washing machine, washing basin, bathroom shower head and bath were very similar. Uga and Ufi (mother and daughter) made photographs of the same wall displaying family photographs near the kitchen at home.

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89 Olo felt satisfied that the photographs produced and compiled by his two adult children participating in the study would be sufficient. This was the reason he selected not to accept the camera and the reason why he did not produce any photographs.

90 Ie’s first attempt at taking photos resulted in a high number of blurred shots. She asked me for another disposable camera to produce better photographs. Efu’s second set, were photos I had taken of Efu at his request. Most of Uso’s and Ofe’s photographs are images produced with their own digital cameras at least 12 months or more before they became involved in the study.
Ata produced the most photographs of ‘framed photographs’ (Appendix 8.1 Ata’s Photo Set). Efu and Emo (Family 2, see Table 5.6 below) produced the most photos ‘doing household chores’ and had the most photographs of small children (refer to Appendix 8.2 Efu’s Photo Sets 1 and 2; Emo’s Photo Set in Appendix 8.3). Ie and Ivi (Family 3) produced the most photographs of ‘public places’ and photos of their ‘workplaces’ (Appendix 8.4 Ie’s Photo Set 1; Appendix 8.5 Ivi’s Photo Set). Ofe and Osi’s photos (Family 4) featured many household appliances and medical equipment. (Appendix 8.6 Ofe’s Photo Sets 1 and 2; Appendix 8.7 Osi’s Photo Set).

All the families (except Ata) produced a photograph of their home dialysis machine and home dialysis medical supplies. Ie was the only participant to make photos of Margaret Stewart House and the Hospital Shuttle; and Efu of the Porirua Satellite Unit.

Family 5 had the most number of family members in the study, but collectively produced the least number of photographs in the study. The only photograph of a family pet was made by Uga (8.9). The youngest person in the dialysis study is Ufi who was aged 17 years of age (Appendix 8.8). Uso was the only one to provide photographs of his family on holiday overseas (Appendix 8.10). Usu was the only person in the study who was self-employed in his own business (Appendix 11).

Table 5-6: Photo sets for all home dialysis participants

<table>
<thead>
<tr>
<th></th>
<th>Family 1</th>
<th>Family 2</th>
<th>Family 3</th>
<th>Family 4</th>
<th>Family 5</th>
<th>Home Dialysis Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ata</td>
<td>Efu</td>
<td>Emo</td>
<td>Ie</td>
<td>Ivi</td>
<td>Ufe Ofe Oli Osi Uso Uga Usu Ufi Total</td>
</tr>
<tr>
<td>SET 1</td>
<td>26</td>
<td>27</td>
<td>27</td>
<td>8</td>
<td>26</td>
<td>18 0 28 0 11 5 17 193</td>
</tr>
<tr>
<td>SET 2</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>23</td>
<td>0</td>
<td>43 28 0 10 0 0 0 107</td>
</tr>
<tr>
<td>All Sets</td>
<td>26</td>
<td>30</td>
<td>27</td>
<td>31</td>
<td>26</td>
<td>61 28 28 10 11 5 17 300</td>
</tr>
</tbody>
</table>
5.2.10.3 Kidney transplantation

The decision to undergo a kidney transplant was a topic discussed by all five families. This was considered as a relatively ‘sensitive’ topic for most of the participants.91

The families of the eldest participants in the study showed the greatest reluctance towards kidney transplantation than the families with the younger participants. Older patients admitted not wanting to involve their adult children in discussions about kidney transplantation. Only three out of the five families had family members undergo formal tests to investigate for compatibility kidney transplantation. Two of the families refused to explore it as a serious option.

At the time of interview, two families (Family 3 and 5) were undergoing pre-transplant workup tests to find donor and patient compatibility. Potential donors were being sought from the extended family and friends. Only one family (Family 5) had by the end of the study successfully completed kidney organ transplantation.

When Ata was told that two matches within his family had been found, he refused both offers for transplantation. Olī had also rejected the offer of transplantation when a matching kidney organ was found from the deceased kidney registry. Participants (Ata, Efu, Emo and Olī) mentioned the following reasons against transplantation:

1) older age of the patient
2) concerns about the dangers of transplantation for themselves and donor;
3) refusal to put family members (particularly consenting adult children) at risk
4) anxiety about the surgical process;
5) refusal to put a family member (donor) at risk in the future of needing kidney dialysis and experiencing the burden of institutional health
6) fears about successful post-operative recovery;

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91 Four participants asked me to turn the recorder off so that they could talk openly about this issue.
7) the perception that transplantation is ‘better and more appropriate’ for younger people;

8) emotional and spiritual decision for the end of life (death).

5.2.10.4 Dissemination of findings for dialysis study

As mentioned earlier, an important aspect of the Photo Voice methodology involves the active and purposeful dissemination of the findings to relevant stakeholders in order to raise awareness of the issues that impact the lives of the participants. This often involves dissemination to policy makers and service providers.

In the home dialysis study, I organised a shared meal for the families about a year after the field interviews were held at the end of October, 2007. At this meeting, which was held at the university and attended by my supervisor, there was unanimous support to hold public exhibitions of the photographs the families produced. A data show of the photos was presented, where participants were able to view their own photos and those of everyone else in the study. Responses from people who spoke from each of the families was appreciation and relief at being able to meet others with similar dialysis experiences. People had gained deep insights about the diverse responses that they and other families had had in dealing with the realities of CKD and home dialysis. A series of subsequent meetings followed over the next 12 months to bring representatives of the families together to discuss the criteria for which photos would be selected for the exhibitions. The objectives and terms of the project was also discussed and members of the group were tasked with investigating local suppliers for quotes, costs and locations. The information gathered by what was a core of five people provided the basis of several funding applications over the course of the next four years.

The first proposal went to the Capital and Coast District Health Board, Pacific Directorate in mid-August of 2008. Tentative approval was given for $10,000 to hold exhibitions at local Pacific church and community venues but the funding had to be spent within a short time frame and at that stage I was unable to do so until the following year because of health and doctoral obligations. Sadly, as a result of the timeframe and also changes in relation to funding criteria, the funding was later withdrawn and we were asked to resubmit the proposal, where we were told the project might at best get half of the original amount. We were also asked to present
the proposal to the Long-Term Conditions unit of the district health board to explore whether they might be willing to fund the health literacy component of the project. Because our proposal included the design of a web-based patient information service for renal patients and a place where the photographs could be exhibited, the funder was reluctant to put resources to it because there was another national similar project being organised at the Ministry of Health and an update of the district health board’s website had recently been completed. While the participants were disappointed with both outcomes, they were satisfied that formal discussions about their project was well established and agreed for me to continue to explore other funding avenues.

I sought funds elsewhere, this time with the Ministry of Health. More discussions were held with the Pacific Directorate and the Renal Unit in support of a proposal to bring together relevant community and primary health agencies to set up an integrative programme for Pacific renal patients in Wellington. There was also an evaluative and participatory component of the project to measure the effectiveness of the programme over two years. The proposal we sought was $90,000 and it was submitted at the end of November 2011 to a private consultancy called Pacific Perspectives Ltd who acted for the Ministry of Health. At the beginning of 2012, we were notified and told that our proposal was one of the best received by the funding panel but that they required more information, which we provided and a draft contract was drawn up. Disagreement arose when the funder suggested that we follow a model being used by the Manukau Renal Unit, which CCDHB were reluctant to consider. As a result, the project came to a hold and the funder declined it on the basis that we did not fit the specifications of the proposed contract. Although disappointed again with the outcome and the time taken by our research team to design the proposal, it was clear that public health funding was wrought with too many barriers.92

92 In 2012, we were finally funded with $1,000 assistance by the Pacific Directorate at CCDHB to reproduce the photographs of the study for a special visit by the Minister of Health from Samoa, Hon. Dr. Tuitama Talalelei Tuitama who was an invited guest of the University of Otago and key note speaker at the Public Health Association national conference. The families of the study were invited to join the Minister and his delegation for a shared afternoon meal and to talk about the photographs that they produced. A special invitation was also made to the Wellington Kidney Society so that a relationship between them, the participants’ group, the Pacific Directorate and University of Otago research team could be fostered. One of the members of the Minister’s delegation included the General Manager of the Samoa Kidney Foundation who offered help and assistance to any of the participants whenever they visited Samoa. Questions were raised about the costs of New Zealand patients dialysing in Samoa and whether there could be an exchange between the participants and the Samoa renal dialysis unit. The participants’ photographs which had been produced on A3 sized canvases and posters were displayed in the meeting room for all to view. About 9 canvas photo frames and 15 A3 glossy coloured photos with captions were gifted to the Minister and to the Samoa Renal Unit to be enjoyed by Samoan dialysis patients and their families. It is hoped that a future exchange might be arranged between Wellington based Samoan dialysis patients and the Samoa National Kidney Foundation. On reflection, this event proved to be an important occasion for the families of the study whom after several years had finally experienced success in
Table 5-7: Family Decisions in relation to Kidney Transplantation

<table>
<thead>
<tr>
<th>Patient &amp; family transplant decisions</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient name</td>
<td>Ata</td>
<td>Efu</td>
<td>Ie</td>
<td>Oli</td>
<td>Uso</td>
</tr>
<tr>
<td>gender</td>
<td>male</td>
<td>male</td>
<td>female</td>
<td>female</td>
<td>male</td>
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<tr>
<td>patient</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>age</td>
<td>72</td>
<td>67</td>
<td>22</td>
<td>70</td>
<td>23</td>
</tr>
<tr>
<td>Home treatment mode for ESRD</td>
<td>peritoneal dialysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>haemodialysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>participant reported cause of CKD</td>
<td>hypertension</td>
<td>kidney stones</td>
<td>Chronic reflux nephropathy</td>
<td>diabetes</td>
<td>nephritis</td>
</tr>
<tr>
<td>family discussed</td>
<td>transplant with immediate family members</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>family discussed</td>
<td>transplant with extended family members</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>family members</td>
<td>underwent pre-transplant workup tests for matching</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>family members</td>
<td>medically suited</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>patient desired</td>
<td>transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>patient did not desire</td>
<td>transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>family member</td>
<td>offer donate kidney</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>patient refused</td>
<td>offer of cadaver kidney</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>patient refused family</td>
<td>offer of donated kidney</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>patient underwent</td>
<td>transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

being able to finally gift their photographs to other Samoan dialysis families, albeit, families not living in New Zealand, but in our homeland of Samoa! Photographs and posters were also gifted to the Wellington Kidney Society in hope to raise more awareness of Samoan dialysis patients’ experiences.

Not one to easily surrender, and feeling inspired by the recent visit of the esteemed Hon. Tuilama, I pulled together yet another proposal to resurrect the exhibition project for Aotearoa-based Samoans, this time to the Lottery Health Fund, for translational research in October 2013. I had to feel a little more hopeful about this proposal because the funder was specifically interested in the dissemination of findings from post-graduate and doctoral studies where the research could be passed to communities and through publications to academic journals. At the time of writing we are still awaiting notification about whether we are successful or not.
5.3 The Institutional Setting of Home Dialysis

In the Wellington Regional Hospital Renal Unit, Pacific patients outnumber all other ethnic groups. The “patient empowerment” strategy of the CCDHB sets out key health goals aimed at maximising patient independence, maintenance and improvement of the quality of life (225). Patients under this strategy are encouraged to do their own dialysis treatment. Key informants at the renal unit told me that staff try and support patients to adhere to this policy.

As was highlighted earlier in Chapter 2, Pacific patients (across all age groups) have very low uptakes of home dialysis, and this has resulted in more Pacific patients undertaking in-unit dialysis than home dialysis, especially when compared across all other ethnicities. Some of the observable differences for Samoan patients is that family members are often with them as carers (82, 137). The other is that many elderly Samoan male patients tend not to do their own dialysis treatment unless they are assisted by staff, tasks they are deemed as being able to do themselves.

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93 Setting up and testing the haemodialysis machine; cleaning the water filter; inserting and taping needles; checking and monitoring machine levels; taking their own blood pressure; and be responsible to self-monitor for potential risks and difficulties.
In the following section, dialysis patients share some of their experiences of dialysing at the renal unit and the range of dynamics they coped with while undergoing institutional care. Figure 5.1 shows the patient engaging with the institutional health services at the ‘front of house’. One of the main characteristics of the institutional setting are the formal rules and expectations that are placed on patients, a theme which arises in the stories of all of the participants.

5.3.2 The hospital a better place than the home

As a carer Emo was convinced that her husband’s longevity on dialysis was due to the institutional services provided by clinical staff ‘at the front of house’. Her greatest concern about home dialysis was in relation to the patient’s obligations of self-directed care and supervision. In her view, the support of clinical staff in the hospital setting is more likely to make the patient adhere and ‘listen to the doctors’ about completing the required hours of dialysis, than if they were at home on their own. Her previous experience of supporting her husband on CAPD for 12 months at home was difficult because he consistently ‘short-cut’ the dialysis routine. She felt responsible and culpable when he was constantly sick and admitted into the emergency department. From the time that her husband started on home dialysis, Emo had no support from the ‘front of house’ or health institution. She blamed herself for not being able to protect him.

Emo: I suppose that’s the main reason why I’m against having the machine brought home, it’s best for me that he goes over there (hospital) so that he can really work hard on his machine, so that he can live longer and have a good life because if he brings it home to do his machine, (laughs) well, then there will be problems and things like that.\(^{94}\)

As a result of being sick, staff recommended that Emo’s husband discontinue home dialysis and return to the hospital. It was a great relief for her to know that at the hospital he would be closely monitored by clinicians whose medical training and expertise protected them if anything went wrong with her husband’s dialysis. At home she felt totally exposed by all the potential risks that her husband suffered as a patient; unlike the doctors and nurses, she as a carer had no formal protection.

\(^{94}\) Samoan Translation: Emo: Pei ole mea lena laiga nou le, tetee au ia ile aumai tua ole machine sili ia te au le alu pea o na ia i tai faamaoni ai le faiga olana machine ma maua ai pea lona soifua lelei umiumi, aua a aumai I tua ia, faiga olana machine, (laughs) tupu ai se fa’alavelave mea faapena.
Emo: The other reason I’m against it [home dialysis], the doctors are there, the doctors are really the ones because they have everything, because they are paid by the government.

For many Samoan families there is a clear demarcation between the home setting and the hospital institution. At the ‘front of house’, medical procedures are largely associated with commercial and legal responsibilities (23). Emo made the distinction between being a ‘mother’ and a ‘dialysis carer’. At home she was satisfied to carry out her ordinary roles as ‘mother’ and ‘spouse’, because it posed no liability on her or any of her family.

Emo: Whereas the work that I do as a carer taking care of the patient, or my work as a mother, it belongs within the family. Going to the hospital, it’s the work of the doctors. If the machine is brought home and something wrong happens to the patient, then that’s what will get me into trouble because I don’t know what has to be done, a?

The hospital built environment – “A second home”

For most patients, the hospital’s Ward 40 (Photo 5.1) and Margaret Stewart House (Photo 5.2) can be like a “second home”. This was Ie’s description of the place where she spent nearly three quarters of her life on dialysis.

Ie: Oh, these photos of ward 40 at the reception… that’s like a second home, like, when I’m sick and that, I’m always there. So it’s kinda like, in out, in out, in out, yeah. That’s why I call it my second home… But I reckon, the most is probably, six times in a year. It’s like every second month, but I’ll only be in there like for a few days or a week or something.

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95 Samoan Translation: Emo: Pei o le isi mea na e tetee pea a’u ia, e susulu atu i foma’ia, o foma’ia e fa’apitoa a lava mea a i latou, leaga o ga e toto gi tupe a le malo, o galuega a fa’ita lea va’ai a ma’a i, po’o o a malamalamame fa’atinia, tu’u i le aiga. A alu ile falema’ia, o galuega lea o le fa’afulafili. A aumai tua le masini pe a tupu se fa’aalavelave ile ma’a, fa’atu ga ua fa’a’aina ta ita, e leai sou malamalamaina a? Pei leaga lea la e tumau fa’ee le’u mafau fu a?

R there’s lots of things like – not enough
In our first interview, Ie explained how patients learn about the indoor environment, and the importance of maintaining a clean and sterile treatment space. At 21 years of age, Ie was one of nearly 6 young adult patients in the renal unit. Photo 5.3 is a photo of her at Margaret Stewart House on dialysis (taken by her cousin). Photo 5.4 is of the hospital furnishings in the ‘family room’ of former Ward 40 Renal Unit and how she viewed the shared space used by patients, staff and visitors.
So they cover it, just to be hygienic kinda thing. Like I don’t even sit on those couches or lie on it or anything. I just sit on the normal chairs, but then, I’m, oh, like I am in the day room sometimes, but … because a lot of people use it, there’s families, patients you know, we don’t know what everyone’s carrying, so, that’s why, people, I reckon why people put sheets on it, just to be safe (um).

The white sheet is a cold and distancing metaphor for death.

‘Cause it’s like, if you look at that couch, if you look at it, what do you reckon? If you first looked at it, what do you reckon it looks like?

Um (thinking), it’s a sheet covering it.

Losing friends in the renal unit can be upsetting especially when institutional rules controls and “covers up” the information that can be communicated in relation to patients’ health and status. In this way, patients who spend a very long time in the same ward can feel isolated and alone by the same rules that are designed to protect them.

…sometimes I feel like they’re saying it just to cover themselves up, so that you, so that they won’t… If I ask, ‘cause I asked them, “How is this person?” And then they were like, “They’re okay.” The day that they told me they’re okay he was already gone! I was like, you know, “You can’t say someone’s okay, if they’re gone!”

So you would prefer them to do what?

Tell the truth, just tell me!
In a place where information can be concealed, the hospital environment is also a place of ‘structure and order’. Ie’s photograph of the dialysis supply cupboard at Renal Ward 40 (Photo 5.5) is the ‘ideal’ storage space that patients at home need for their dialysis supplies, an aspect of the institution that offers a useful and practical system for managing long-term illness.

![Photo 5.5 dialysis supply cupboard at Renal Ward](image)

**Ie:** I took this photo ‘cause I reckon that people that are doing home dialysis need something like a cupboard like that), for storage. Because...we get all these boxes and stuff...everyone probably just keeps it in boxes. Oh, I know some people that have like um drawers, but even that - it’s still...in the way...I took that photo just so like, that’s a good option to have in the home with the store cupboard. ‘Cause it’s got all that connected...and it’s just easier, so like every time you get um new stock and stuff, you can just grab it and just put it all in, crush up all the boxes and throw it away, instead of like, just leaving it yeah kinda thing.

Without ‘orderliness’ dialysis can become chaotic and messy. Below, Photo 5.6 Ie compares the hospital cupboard (above) to the family laundry room at her house that was used to unpack medical supplies. At home the children of the family, Ie’s younger siblings, were responsible for ensuring that dialysis consumables were taken from this room and to the haemodialysis machine upstairs in Ie’s bedroom. Over 12
months it became a stressful and exhaustive aspect of home dialysis for both Ie and the rest of the family.

Photo 5.6 dialysis supply room at Ie's home

Ie: And this is my messy box room, this is supposed to be our wash house. And as you can see there are a lot of boxes, and as I mentioned before it's like, yeah, the storage, the storage space. (Pause) 'Cause, I have heaps down there that you can see, like little saline’s hanging out, needle thingies, bath tub (laughs) someone just threw that in and mats!

Photo 5.7 is Ie's haemodialysis machine at the renal ward a few weeks after she gave up home dialysis.

Photo 5.7 Ie's haemodialysis machine

Ie: And that's just the blood on dialysis. That was just dialysis, blood, being on dialysis at the same time, and it's just the going around the machine.
5.3.3 Lack of information within the hospital setting

Other participants in the study acknowledged that they also had difficulties communicating with staff and getting important patient information they are entitled to. It took Uga and her family three months to find out that car park subsidies were available for patients regularly coming to the hospital for appointments three to four times a week, particularly when parking cost more than $5.00 each visit. She was concerned that many families who come to the hospital can find it difficult to be assertive in order to get the most basic information within the public health system.

_Uga:_ Yeah…some people won’t ask will they? That’s the thing, no.

Ivi was a young mother when she entered the public health system and had to engage with clinicians about her daughter’s CKD. She said for years she felt compelled to put on a “brave public face” because “privately” she blamed herself for her daughter’s kidney disease and reflux nephropathy.

_Ivi:_ I remember that day…I was only young [15 years old] when I had le and I was growing as a mother with her…for a long time kinda blamed myself, why she ended up on dialysis…

Each interaction she had with staff made her anxious and for several years she found it difficult to ask questions about what was really happening to her daughter.

_Ivi:_ I felt really uncomfortable…not really understanding, ‘cause they used all these big words and things, and, I couldn’t really ask to get clarification, because it, at that time, I respected what people, say, said, and just thought, “Be a listener and just listen”. But not really understand, and I was kinda confused.

One day, Ivi made a formal complaint about a nurse who criticised her for being a young teenage mother. She found the courage to speak up for herself but knew that many Pacific people lack the assertiveness when dealing with officials.

_Ivi:_ …the nurse said something and it was really out of this world, “Oh, no wonder she has this sickness, ‘cause you were young, a young mother!” And I went to complain to the head person… I was really, really hurt…that just came out of the blue…She came apologised, and that’s when I decided, “Okay, I’m going to go and um, go and do some studies, social services (laughs), just to, so that I can get a better understanding, and also to help me with my English and education”.

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The incident helped her realise that parents need more support to resolve the anguish and frustration they experience from having to deal with issues in relation to the public health system.

*Ivi:* Medical people, yeah, I used to get really angry...and I would yell, and then they'll...try and get someone to come and talk to me, like a nurse or something, and I said, "That's all I wanted to hear," you know, "it's pretty simple! I'm asking a question, 'cause I need to know what's going on with my daughter!"

Dealing with the expectations of the extended family about not being able to do paid work often drew criticism; it was another pressure that Ivi had to cope with. The constant strain of caring for a young child on dialysis created major issues between Ivi and her husband, and they separated on more than one occasion.

*Ivi:* So, that um, 'cause it was really hard too...and my dad, like a lot of people say, "Oh, go and get a job!" You know won't mind their business and things, but I needed him (husband) to look after the kids, while I concentrated on Ie. I didn't want him to work 'cause I needed him at home at nights especially when I had to go into the hospital and stay there...

Ivi suffered constant financial and emotional hardship while taking care of her sick child full-time. Photo 5.8 is the train station where she used to park her car on sunny days and catch the train to work. It was a reminder of the previous years of hardship when she could not afford the fares to take her daughter into Wellington for her dialysis appointments.

*Ivi:* I'd never leave her on her own...from since she started going to hospital...she had her operation when, she started on peritoneal and that was really tough...And we had no transport at that time, it was either get the bus and train, and there'll be times, when...we used to miss um, appointments, 'cause we couldn't afford to go...she got sick...we'd go, you know go get go the freeway in...we'd get an ambulance...my kids were little, they're just little kids and little babies themselves.
In consideration of the hard realities of her daughter’s dialysis, Ivi said that it took nearly three years before she found out that there was a free hospital shuttle van that operated between Wellington and Porirua. It angered her that no one from the renal ward had cared to tell her.\(^9\)

\(\text{Ivi} \quad \text{It was really hard on the benefit, when we were on the benefit, travelling in and out of town, and not understanding, not knowing that, um, there was a shuttle service. And not knowing that you could get a parking ticket back then, didn’t know that. I had I found out probably three years after that this was going…And um, then…we were paying off our vehicle as well…there was times when, it got a bit too much and my husband and I had to part for a while.}\)

Photo 5.9 Ivi’s photo of the free hospital shuttle

The hospital setting is viewed by participants’ as being better resourced than home dialysis because it is attended by clinicians; however, as will be discussed later, families are more likely to find relevant information that can help them about non-clinical matters like benefit entitlements and transport by looking outside of the hospital system.

\(^9\) It is approximately 17 to 20 kms between Porirua to Wellington hospital.
...Was it a WINZ, some kind, can’t remember her name, ah, some kind of representative in the hospital that tells you what you’re entitled to, who can, oh consults whatever with ah your WINZ people about your benefit, um, and she was pretty helpful, I can’t remember her name… she’s a, some kind of social worker, and um, yeah they were pretty good at telling me what I, what I’ve claimed for, or try to. ( ) my doctor was pretty good with that too, he told me that I can claim for you know like, as well as petrol, like cell phone, in case I need a cell phone with me for emergency, like, there’s actually quite a bit you can claim on.

5.3.4 The Institution of “able” and “unable” patients

One of the most important components of the institutional setting is the way that clinical staff engages with the dialysis patients. In the interviews, most of the participants spoke positively about their renal physicians and a few identified some of the nurses who they liked in the renal ward.

Ata (elderly male, aged 72) spoke affectionately about a male staff nurse that showed him a lot of “love and compassion” fai galuega alofa with patients. Ata formed a close connection with him because he also showed deep commitment and dedication, fa’amaoni in his work. The nurse was “always willing to assist patients” fia fesoasoani mo tagata mama’i a trait which is consummate with the ‘service’ tautua (compassion and respect) in Samoan culture (Chapter 3). Elderly people like Ata are inclined to compare institutional roles of care provided at the ‘front of house’ to those in Samoan culture such as ‘taulasea’ or traditional healer and tausi ma’i and tausi matua ‘carer roles’.

Ata: Oh, because, he was so good that man (nurse)! Before he left. I had a lot love for him, because this is the real definition of someone works dedicately with alofa (love) when handling the patients, a? He is a very good man!97

Ata was less complementary about other staff in the ward. He described them as unreasonable and uncaring tagata puapuagātia; incentivised by financial gains rather than wanting to help patients.

Ata: Some nurses, they don’t smile, they don’t have any patience. Other nurses are extremely rude (ole matuā rude a); with absolutely no compassion or love (le leai ma se alofa)! The only reason they’re there is for the money, aye?

97 Samoan Translation: Ata: Aua ole lelei ia ole ali, ae lei alu ese mai, I, coute alofa a iai foi leile, mea tonu lea e tau ole tagata foi lele faigaluega alofa I mea o patients a? lelei ia ole tama.
Underlying this perspective was Ata’s frustrations of how staff tended to treat patients unequally.

Ata: Yet, there’s another patient who I see whenever he comes in, the nurses run around for him, do his needles, get him blankets and do everything. Yet that guy, he has caused a lot of problems here for the staff and the other patients.98

He often disagreed with the dominant view of staff that he should do his own treatment without their help.

Ata: I had an argument with ( ) the other day, “If you want me to set up this dialysis machine, then you’ll have to pay me to do it! I’m not going to do it for nothing - because otherwise, if I do it, you’ll get all the credit for just sitting around and drinking coffee!” That’s the thing. Oh, she hates my guts.

He finally realised that much of his frustrations with staff was the way that patients were cast into two distinct groups. “Able patients” were those physically able to clean their dialysis machine and insert their own needles. “Unable patients” were those who could not do any of these tasks and needed staff assistance. Ata was repeatedly told that he was an “able” patient - a label he refused to accept.

Ata: What I’ve seen, is that those patients who are ‘able’ to set up their machines, like when they come in the morning, set up their machines, do their needles, do everything and all they’re doing, the nurses, is drinking their coffee and reading the newspaper! It’s only until it’s someone really needs [help] that they’ll come forward.

Things got worse in the renal ward when an announcement was made about the dialysis schedule and that the “able” patients were no longer permitted to dialyse at Ward 40,99 but had to relocate to the new satellite clinic in Porirua.100 Ata despaired about having to travel 120-150 kilometres to Porirua each week to dialyse; a situation which would make him more reliant on his family in terms of transportation.101 He out

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98 Samoan Translation: Ata: “Ou sau ae o atu le au tamaitai na ilalo i Margaret Stewart avatu mea foia e line ai le masini. Ou fai atu aute le tago lava ise mea o aute le faia se mea, ia aua ole mea lea l i lau vaai iaia, o tagata nei e matalia faia a latou a masini, ma o atu a lea ile taaeo faia le latou masini line tapu latou nila faia uma a mea uma ae ia e inuinu koe ma faattau pepa nurses. Seloga ua oo le taimi foile ilea uma ai ina fa’ataga o atu lea e faasoasaoani 1 o fai lele. I na ma argue ai faoa lea ma ( ) ile ise aiso, ou fai atu ae manao ia te au aute faia le masini lenei ua have to pay me I’m not going to do it for nothing. Aua lona uiga e fai e au ae credit ai outou, nai le tou nofonofono ma tou inuinu kofe, ioe, ia ole mea lena, oh she hates my guts. Ae ise leisi ali ia ei ia, ia ( ), e le tago a e fai se mea, nai le alu atu a ile taaeo ile nofo l i lao ae o atu uma a nurses faia uma a mea ma ta tul nila avatu tia lana palanikeke ma mea uma a.”

99 The Ward 40 was located in the Ward Support building of the Wellington Hospital. It was shifted over to the newly built premises and renamed as Level 5, Dialysis Unit as part of the Wellington Regional Hospital. (check)

100 The Porirua Satellite Unit has one of the highest attendance of Pacific patients in the region.

101 Two patients dialysing at Porirua lived as far as the Hutt Valley (60km return each session) and Kapiti Coast (120 km return each session). Another patient who had to dialyse at the Wellington renal unit travelled from Porirua (40km return each session). Reimbursement through the National Transport Allowance Scheme is permitted for patients who live a maximum distance from the dialysis unit. I was unable to ascertain the exact formula that was used to calculate the reimbursement but only one of my participants (Kapiti) was able to claim reimbursement and was awaiting payments at the time of interview.
rightly refused to adhere to the new schedule and found himself embroiled in another heated argument with staff.

Ata: Me, I said, “I’m not going to Porirua! I live here [in Wellington central]! I live practically on top of the hospital! It only takes me five minutes from my place to the hospital! So are you going to take me to the Porirua clinic?”… It’s alright going there - but it’s the coming back after the treatment… for me it’s (my health) really changed I don’t know about other people (patients), but for me, as long as my son [comes], as soon as my treatment’s finished, I just get into the car, come home, make a cup of coffee, then have a rest. 102

Although Ata had no choice but to travel out to Porirua, he continued to complain and was allowed to return to the Wellington hospital to do his dialysis. When patients are dissatisfied with the dynamics in the ward, they often attribute a patient’s death to what is happening between the staff and the patients.

Ata: There’s some who get there, rush, rush and the poor patient is struggling by themselves and that’s what happens, next you hear the patient’s dead - must be because they didn’t get the help! 103

As Ata reflected about why he was determined to speak out about issues he disliked at the renal unit, he recounted his experiences as a church leader when he fought to protect the members of his congregation against the autocratic and bullying tactics of a former church minister. 104

Ata: But, he wasn’t a good person (church minister). He came over, because he was at the Palagi church and bearing in mind you know, at the Palagi congregations there are lawyers, judges, doctors and educated people. Here at our church, we’re people you know who are not well educated and that kind of thing! 105 (Sarcastic and laughing)

However, participants who travelled from Hutt Valley, Wellington and Porirua to the satellite/hospital in-unit clinics were not able to claim reimbursement.

Samoan Translation: Ata: “Aua fai mai le tamaitai o ( ) ia au e lua ituaiga a patients,ole able ma le unable. O matou la nei e able lea e feave’aii e ave I Porirua, o au ua le toe ave foi au I Porirua na ma argue foi, ou fai atu oute le toe atu I Porirua olea coute nofo ii toe itili ou nofo ile falemai, it only takes me five minutes to my place to the hospital. Ae ete ava au I Porirua le mea ole mai. E lelei la foi, its alright ile au ao le sau la lea foi ile aftter ole treatment, ia au a matua esse tau fa’alogo foi lele tailo iai isi tagata ao au ia pau a ole mea e alu atu loa lounatali e uma le treatment nao lou oso a ile taovalo ou sau nei le fale, sau a fai se ipu kofe ou alu loa ou malolo.”

Samoan Translation: Ata: “E matuai hard case a isi patients I lata ila lava vaai isi, foi ile ona ole, o isi nurses ole matua rude a, matua le leai ma se alofa the only reason e alai ona alu atu l o is for the money a? Ae le’o le agaga foi ile e fia fesoasoani mo tagata mamai ma tagata puapugatia. O leisi au matiai na ona o atu a tatope a o, ia ae struggle ai a le mai latou l o, mea foi na e o atu ai ua fekoti isi mai’a ona ole le fesoasoani.”

A short time after he resigned, the minister and his wife approached with an apology. However, it was too late and a series of major complaints from other parishioners led to the eventual removal of the minister from his post at the church.

Samoan Translation: Ata: “Ae ilea Ia ile igoa, e sau foi ile, au a sa ile ekalesia palagi, la manatua oe o ekalesia palagi latou e ia ioia, faamasino, fomai ma tagata popoto. O l’ie auloto lea a maitou o nai tagata foi lea e le lava malamatama e mea faapea.”
Within the Samoan community, advocacy is considered as an obligation at the front of house, and leaders like Ata take up this role naturally when they sense that the institutional arrangements are unfair.

Ata: I was a church leader... I'm really satisfied I did so much for people...built the hall, built the church building. I was a church leader. I hope that I will be recognised by others that it was something I was part of. But then, that's the trouble, some people have no perception at all about thinking about it in this way. And, so now since I've moved away from that responsibility, I hope that it will be recognised and enjoyed by others that it was something that I was part of doing.

Another Samoan elderly man who was viewed by other patients as holding mana and leadership like Ata was Efu. At the satellite unit, Efu preferred to carry out his own dialysis treatment because he wanted to be self-sufficient and independent, not wanting to rely on others for help. While Ata was at least 10 years older than Efu, the differences between the two men is worth exploring because it highlights the way in which this particular group deal with institutional arrangements and how they cope with chronic renal disease. As will be shown later, Efu’s primary motivation for independence stems from his cultural beliefs as a Samoan orator and on other traditions such as the Samoan tattoo pe’a, traditions at the ‘middle of house’ that I discuss in the later part of the chapter. Suffice to say, Ata’s sense of injustice and Efu’s motivation for independence are two separate and equally important approaches for dealing with the dynamics at the renal ward. Below, a photo of Efu undergoing dialysis (Photo 5.10), and the dialysis disposable products that he used for treatment (Photo 5.11).
5.3.5 Weak primary health care links to the renal unit

Olo’s family made the decision to commence palliative renal care for his wife and so, the hospital sent them back to their general practitioner to do home visits and administer pain medication. Prior to this, the patient’s main health provider was the renal unit and so the transition back to their primary carer happened only towards the end of life. While this was not problematic for Olo’s family, it highlights the shift that occurs when a patient is engaged predominantly with the secondary health services. This was the experience of other participants who became more involved and more reliant on the renal unit for most of their health care needs.

Uga’s family lived in a semi-rural area and their house was 60km away from the renal unit in Wellington and they had concerns because of the distance from the hospital about getting adequate help during an emergency. When her son Uso, suffered a seizure during his haemodialysis session at home, the family called an ambulance and he was immediately taken to the emergency department in Wellington. Uga contacted their family primary health service where they attended for 20 years and was told that their family’s medical records were not on the computer system. After making a complaint about the rudeness with which her family’s case was handled, Uga felt disappointed that the care she used to receive from a “dedicated family doctor” was lost because the primary provider had become “so big” after amalgamating with a number of other practices in the area. Uga’s main concern was having a medical service that ‘cared’ about them and more now that Uso’s CKD was life-threatening. Like Olo, Uga felt that there needed to be much stronger links between the hospital and primary health services so that patients could access the best of both services.

5.3.6 Young people feeling out of place

One of the important issues that were raised about the hospital environment was the differences of ages between patients. Uga soon understood why the renal staff had taken her son aside to warn him not to be surprised that most of the patients were elderly.

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106 Samoan Translation: Efu: Pei a se mea e fai uma...pau a le mea sa faigata foi le gale, se manogi ose mea’ai, poo feau uma a ma mea uma a talu maia ona ou mai sa fai uma a ia, pei foi ona ou fai atu, le faatuutu le mai.
...she (staff member) actually said to Uso, “When we go in there, you need to remember the people that are dialysing in there, have other medical issues.” There was no one his age, and there were some really sick man… I know they're cramped for space…but one day he was in there dialysing and there was a guy next door to him on a bed, with an oxygen mask, and quite honestly he just looked like he was on his last legs.

On her first visit, Ufiufi (aged 17) noticed that there were splattered blood stains on the walls. Seen through her youthful eyes, institutional care seemed like an unpleasant place for her brother (aged 23) and other younger patients.

R: Why do you say it wasn't nice?
Ufi: Um, (pause). It just looked a bit old, you know. It was (giggles) even the room where everyone was on dialysis, there like blood on the roof (giggles), on the ceiling. ‘Cause like, sometimes when they put the needles in, like I can't believe it squirts that high. But I think they should wipe it off 'cause it looks really gross! And like the nurse had this really big shield over her face and Uso was like, “Why are you wearing that? She goes, “Oh, just in case it squirts me when I put it in.” (Giggles).

She said she felt ‘sorry’ that her brother “did not seem to fit in” because he was much younger than most of the patients in the ward.

Ufi: You've got the youngest one there, they're all really, like their either really fat, or just look gross (giggles)...just seemed like he [Uso] shouldn't be there, yeah... it wasn't very nice, but I guess, no hospital's particularly (giggles), nice to be in.

5.3.7 Summary

The institutional environment is dominated by order and structure. Like the La'i, a wind that has lost its momentum and passed by, participants were disappointed that no one had informed them that there were parking subsidies and free transport available for patients. Many families had already suffered great financial loss and tremendous emotional stress, trying to get to dialysis sessions at the hospital and so finding out at a much later date made them upset. For most participants the institutional environment was a challenging and difficult place, so much so that they were compelled to question and challenge those in authority about changes to dialysis schedules and the lack of empathy shown by staff. Being assertive in this context is similar to summoning the Fa’asulu, a wind which goes straight to the heart of an issue, and an approach that elderly male patients like Ata and Efu employed regularly in their leadership roles as orators. When Ivi and Uga registered their
complaints about the staff that dealt discourteously with their cases, after they asked for medical information for their children. The prevalence of CKD is higher for older Samoans but is steadily increasing for younger people. In the renal unit the age differences is particularly noticeable and participants of the study expressed the need for more to be done for younger patients. In the next section, participants talk in detail about dialysis within the home setting.
Section B – Back of House

5.4 Adapting the Family Home for Dialysis

This chapter is named to highlight the way in which four ordinary family homes were adapted for the public provision of home-based dialysis services.

Ivi and her family’s story began about a decade ago when they struggled to find adequate accommodation for their six young children. The only houses the family could afford were small, damp and cold. They were wait-listed for a state house and finally were allocated a large renovated six-bedroom HNZC property. In their new home, the family faced new problems, which over time, impacted negatively on the Ie’s ability to dialyse safely at home.

Osi’s family home was older and difficult to warm despite it being recently insulated. Like most of the families in the study, being cold made dialysis an uncomfortable experience. Families have adapted their homes to allow for the massive quantities of medical supplies associated with both home haemodialysis and peritoneal dialysis, as well as for palliative renal care. These adjustments made by families are largely to improve the functional spaces of the house in order to better manage the medicalised activities required from the formal care of dialysis. As mentioned before, the range of activities extending from bathing, ablutions, laundry and preparation of meals are associated directly to the ‘back of house’. Figure 5.2 highlights these on the left side which, more importantly, have to be viewed as overlapping with the formal services provided by the State on the right side.
Adapting the built environment for home dialysis

5.4.1 HNZC renovation and a large electricity bill

When Ie was aged 11 she required APD (automated peritoneal dialysis). Her family moved into a three-bedroom private rental property that cost $230 per week and because it was a small house, half of her medical supplies had to be stored in the bedroom where she slept. The numerous other boxes were shifted to the underground basement and stored on ground surface that was not covered. The house was located in a valley which often exposed the boxes to damp and water.

*Ivi:* You had to walk outside to get to the basement…oh the basement is part dirt, and little bit concrete for your lawnmower, you know for your gardening tools…Under the house…But back then, we had to stack all her um, all the supplies…and that was like she had to go down in the basement…and this would be winter, summer, all seasons, grab the boxes and that…making sure that the water doesn’t run under the house or get damp and then ruin the boxes.

Like other large-sized Pacific families, Ie’s parents tried searching for a bigger and more affordable house. It was difficult for them to manage the overflow of supplies that were delivered for their daughter’s dialysis.
Ivi: Then um, it was about, making sure the boxes were organised, stacked properly… take the bags out of it and put them somewhere else…and then they used to overstock us, and then there won’t be enough room in the basement and then it was getting a bit out of hand, because it was taking up a lot of room.

After nearly six years of being wait-listed for a state rental, the family were visited by a Housing New Zealand Corporation (HNZC) case manager who carried out an urgent assessment of their accommodation. Shocked at the appalling conditions of the house the family was reprioritised for a larger state rental property.

Ivi: Oh, boy, she just, she was shocked…that we were using the basement as well as another room. Whereas we were putting the kids three in one room, Ie had her own room, and then me and my husband was in another room with our two babies.

And then, she was just nodding her head and looking at our house, and saying, “Oh no, this is not right!” and then she came went in the rooms…We had mattresses stacked up, so that when they slept, we put the mattresses down on the floor for them. And then she… saw the mould, and the dampness, ‘cause we were right by a gully kind of thing, and um, you know she goes, “So, have you got three children sleeping here?” I said, “Yes, we’ve got three here, and we’ve got Ie in the back room. She’s got her own room because there were some more supplies in her room as well, plus her machine, her compact machine.

In the year 2000 the family moved into a two-storey HNZC property. Typical of 1950s HNZC multi-units, the upper level contained three bedrooms, a bathroom and toilet; on the ground level there was a lounge, kitchen and internal laundry. Approval was given for both levels of the property to be renovated and this involved joining the upper level to an adjoining multi-unit property next door to where the family lived. This effectively increased the number of bedrooms upstairs from three to six and gave the family an extra bathroom. Downstairs, the partial removal of a wall in the sitting room expanded the family’s living space.

5.4.2 Bigger house, colder house, bigger electricity bills

Ivi’s family were very excited at the prospect of the extra space created by the renovations; it was a “luxury” compared to the damp and cramped houses that they previously occupied.

167 Compact machine is probably for Automated Peritoneal Dialysis.
One of the major changes that occurred as a result of the improvements to the house was that Ie had managed to convince her father to allow her to have a haemodialysis machine installed at home in her bedroom. Ie’s mother was also involved in persuading him about this so that Ie could organise her studies around her dialysis schedule.108

Ivi: I really, I was so overwhelmed, ’cause then that travelling and that…My husband didn’t really agree to her having her machine here, ’cause she still, he still felt that the docs and the nurses need to keep an eye on her, when she was there. I says, you know we talked about it and says, “You need to give her time, see how it goes.” But, it still didn’t work.

The other major change for the family because of the increased indoor space was the extra electricity they were using to warm-up their house. With more electricity use the family’s household energy costs increased and this put them into financial debt and hardship (Photo 5.12). The family then investigated options for switching to a different electricity provider that offered pre-pay-metering. When they made the switch they believed that it was going to be more affordable and more convenient in the long term. But when the credit on the pay meter ran out, the family was plagued by frequent disconnections.

Ivi: ’Cause we can monitor it and that when the power was just so high, we couldn’t believe it.
R: What were your bills like?
Ivi: Oh, it was like over, it was nearly $400, three to four hundred dollars a month.

Unhappy about their situation Ivi called the electricity company who did an inspection of the property’s electrical fuse box and found a fault with the adjoining unit’s electrical wiring. The family were told that the only way to fix the problem was to have the fuse box replaced and that it was going to take a long time to do because the company had a lot of jobs listed before they could work on it. The family were disappointed that the pre-pay meter had increased rather than diminished their energy expenses. Because they were unable to switch back to their previous electricity provider, the family were stuck with the pre-pay meter and regularly suffered power disconnections for non-payment.

108 Her father agreed for a haemodialysis machine to be installed at the house despite his belief that going onto the machine was for him a major sign that his daughter’s health had deteriorated.
At home, Ivi noticed that her daughter had lost confidence in doing her dialysis. Maintaining a hygienically sterile environment requires a lot of effort and Ie had been extremely distressed by events at home and her health.

Ivi: So went through that...and then, when she gets stressed or angry...she'll make, she wouldn't insert properly, and um, she hasn't been keeping up with her, um, tidying up her machine and things, and keeping it tidy and clean all the time, and I think it was the environment.

One of the major challenges for the family was helping Ie to feel warm and comfortable in her bedroom. She complained constantly about the cold, especially whenever she finished dialysing. Photo 5.12, Ivi’s photo of their state house.

Ivi: ‘Cause having the machine here, because...it played up, and then in Winter, it’s really cold here...while she’s dialysing...Not comfortable, enough...and then even...asked her if she wanted a lazy boy, make it easier, but I think it was just the coldness of the room itself...and it was a bit much too...

Photo 5.12 Ivi’s renovated HNZC duplex

In response, her parents placed two free-standing heaters to improve the bedroom’s indoor warmth. They purchased better quality bedding and even removed the floor carpet because Ie was sneezing a lot from dust mite allergies. However, Ie continued to feel cold and more significantly the family experienced on-going frustration and anxiety from the power being disconnected for unpaid electricity. On one occasion when the power was disconnected, the lights in the house went off and Ie was in the dark trying to insert needles. Her machine became inoperable because there was no
electricity and then later in the night she became very unwell, feverish and delirious.
The family called an ambulance and she was admitted to the emergency department.

Ivi: Since we’ve been in this place, and we’ve always had our power disconnected, always one side, and only because the wiring hasn’t been rigged properly and it’s still the same. So we went and got a in-charge thing, which was alright, but when we run out of power, then we’ll have, then Ie was kinda in the dark, um during her needling, ‘cause the power’s just run out, and then we have to go down and buy some more, and put it in the meter.

5.4.3 Space, sterility and technique

There were other issues that made her unhappy. The first was that her dialysis machine and the supplies of disposables took up a lot of space in her bedroom.

Ie Like I’d just want all that in one room, and just have a different room, for, oh like - just my own bedroom kinda thing... and then, all of a sudden, I just kinda like got sick of it, like just the whole looking at it in my room...cause it’s like real big, and it takes up a lot of room. And, not only that, but like, I couldn’t like change, because I’m like real, I always change my room around, like the things in it...and then, because the machine was there, it had to be the same, like all the time, and I got sick of looking at the whole boring setting all the time, kinda thing. And just the supplies, all the supplies and that, it was just stacking, and it was just like getting annoying, I don’t know, I just got sick of doing it at home.

The other was that she suffered a series of skin infections through the vascular access site in her fore arm (Arteriovenous fistula). There was a bout of allergic reactions as well to sterile hand cleaners and adhesive tapes which she used in treatment.
Ie  So I use this sorta tea tree wash, because I, I got allergic to that Microshield…and I got allergic to the Chlorhexidine, that’s the stuff that before you put the needles in, you’re supposed to clean your arm with…So, um, what’s it called, I use saline, just normal saline, so I just clean my arm with that. Um there was another technique that they gave to me, that really helped…I use the Hyperflex tape…but it’s alright, as long as it works, then, I’m happy. Yeah, so I haven’t got the infection now for like three months now, oh, but I’m still on antibiotics as well at the same time…

Ie felt that it was becoming more and more difficult to dialyse at home without proper assistance. After nearly 12 months on home haemodialysis, she made the decision to go back to the renal unit to get more regular help with needle insertion and medication.

Ie  I was buttonholing\textsuperscript{109} and then I started getting these infections staphylococcus aureus in the skin…and they reckoned that it was from my fistular. So just have antibiotics, go home, go back on it, or go to Margaret Stewart and get an infection again…

A few weeks after I interviewed her Ie had her haemodialysis machine returned to the hospital and she stopped dialysing at home. As a way of coping with the frustrations she was experiencing, Ie often went to her grandfather’s house where she had her own bedroom (Photo 5.14) and found respite there until she was ready to go back home to her siblings and her parents.

Ivi ‘Cause um, they’ve moved around her fistula …they’ve tried different areas to insert, but they’re not working… And she said, “Oh, Mum, I’m gonna go to the Margaret Stewart House ‘cause I don’t feel confident enough to needle, ‘cause it’s bit too high, and um, I can’t cope at home with the house.”

Photo 5.14 Ie’s third home – a picture of bedroom at her grandfather’s house where she escaped for time out

\textsuperscript{109} Buttonholing: Is a self-cannulation technique where a blunt needle is inserted precisely into the same hole made by a previous needle stick.
5.4.4 Independence on home dialysis

Efū and Emo were an older couple. Their HNZC property was already modified for individuals with restricted mobility and disability. In Photograph 7.16, Emo stands outside a single bedroom that was formerly her husband’s dialysis treatment room. Here he stored his peritoneal medical supplies, almost a year ago he stopped dialysing at home and in this chapter they talk about why dialysis at home was so difficult to do.

![Emo vacuuming the house](image)

**Photo 5.15 Emo vacuuming the house**

**Emo** It’s true, the house is Housing [Corp NZ] - helped out by Housing, yes, because this house - the reason we got it, it’s a house for people with disabilities, it’s also got a ramp, that’s why we were given it...  ![110](image)  Well right from the start, with the bag, yes, there was a room he used specifically where he put all the things for his treatment.  ![111](image)

In the interview, Efū looked back and said that he had completely underestimated the effort and commitment required to maintain a sterile environment at home for dialysis. He was relieved when his specialist recommended a switch to haemodialysis at the hospital because he did not have to deal again with the high volume of medical supplies used in peritoneal dialysis.

**Efū** So it’s much easier on the machine, because sometimes on the bags, you forget to wash your hands, right? Yes, there might be a lot to do on the machine, but then I suddenly remember what it was like - and everything involved with doing the bags! Boxes, so many boxes and it wasn’t just boxes with the dialysis bags in them, there were other boxes with things that you had to use as well, so many things!

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110 Samoan Translation: Emo: “E moi ole fale ole housing, ia mafai fesoasoani ia le Housing I, aua ole fale lenei, na alai na aumai matou ona o le fale ole tagata mai faapea o fale mo tagata mama’i - taga’i foi la ile ramp lae ia ole mea la na aumai matou inei ae...”.

111 Samoan Translation: “Ia ole amataga maiga ole faiga o mea ia o togoftiga ole taga, ia e sao, sa iai le potu faapitoa lava mo ia sa tuu ai mea uma mea faapena a?”
The switch to haemodialysis took a little getting used to but eventually Efu said that he became proficient in doing everything himself.

Efu: But with the machine, there’s nothing like that, it’s just the machine there like at the unit. I like it on the machine, because on the machine, I get there, get it ready, do all my needles, the only thing I need to do is to ask the nurse to come and set it so that it gets the correct amounts of fluid from my body, and so forth. That’s why I really like the machine.\(^{112}\)

Initially, when he agreed to take up home dialysis, Efu was attracted to the freedom of independence and organise dialysis around his family’s lifestyle and outside commitments. However, it resulted in many admissions to the emergency department; the worst episode involving a blocked catheter which caused a major build-up of toxins in Efu’s body.

Efu: As I said, I didn’t understand all the extra complications involved with the bags (CAPD). I thought it was going to be easier, because I’d heard that if you want to be free to come and go, they’re able to deliver their medical supplies and that’s why I agreed to the bags at home (CAPD). So, it was going for about a year, but then nearly every week I was taken to hospital. There were a lot problems with my physical condition, a? It was when I nearly died, that the doctors said that there was going to be some changes here (pointing to his abdomen).\(^{113}\)

Technique failure can often lead to peritonitis infection and is normal amongst home dialysis patients (226).\(^{114}\) Emo often dismayed when she saw her husband ‘short-cutting’ his dialysis.\(^{115}\) For her, ‘home’ was not an appropriate place for dialysis; the ‘hospital’ is because clinical staff are there to supervise and assist.

Emo: Going along, doing the treatment, [he] wasn’t committed to it here at home - this person (Efu) but it goes onto the responsibility of the Health

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\(^{112}\) Samoan Translation: Efu: O le faigofie la ga i te a’u ole machine lea, ile fo lo mea ga e tatau ai, ae manatua oe, o taga e iai isi taimi e galo ia ia oe na fufulu ou lima, a? Ia po’o ole a lava la le mea fai te’i a ua oe manatuaga loa le taimi ole taga... Pusa uma na sa fau uma I o, ele fa’apea na’a pusa o taga iai fo’i ma pusa o mea fa’aaoga foi gale a? Ile tele o na mau mea, a’o le machine la ia e leai ni mea e tele foi gale, na’o le machine o mea ia lae i tai, e mo’i a lae tele ae la e tele i tai. O Io’u fa’afai na ga la ile machine, lea iai I nei laga fo’i la le faiga o le machine, ia ote latu a’u ia fai le machine, fai uma tui a’u nila, pau le mea ou te fai ile teine foma’I ile sauga e setiga le afa’iga le fluid e ave ese ma Io’u tino, ma mea fa’apena. O le mea lena e lelei iai ia te a’u le machine lea.

\(^{113}\) Samoan Translation: Efu: Na ou fai atu, ou te le malamalama fo’I gale, po’o a nisi fa’afitalui e tutupu mai iai le taga Fa’apea a’u ia, lae e faigofie, aua e lea ou te fa’alogo atu e mafai a ga, a’e fia alu I fea po’o fea, na ona ta’u atu la, mafai a na deliver Io I latou mea, na o’u ioe ai la. Ia alu’ai a lea, pe fasi ea pe le’i ato’a se tausaga, talu ona ou iai le mea na, a’o le mea a ga ga e ta’i vai aso a ave a’u tai ile fa’alema’i. Ia fa’afaletonu atu a la mai Io’u tino, a? A’o le mea mulimuli a lega na iai, lea na fenu a e I’u ai Io’u ola ga, fai mai loa le vaega la sui ia e fai mea i’i (pointing to stomach).

\(^{114}\) Blocking of the catheter tube can be caused by various reasons: kinking of the catheter and inflow and outflow obstruction; excessive catheter motion at the exit site, leading to induration and possible infection and aggravation of tissues 226.

\(^{115}\) The number of exchanges on peritoneal dialysis a patient does per day can vary from 3 to 6. Each exchange can take up to 30 minutes. It requires the patient to attach fresh dialysate bags to a catheter in their peritoneum cavity and allow the dialysate solution (glucose to flow into the abdomen to flush out excess water and toxins. Discolouration (cloudiness) of the waste fluid from the abdomen can give signs of infection in the abdomen. Handling the catheter requires the patient to have very clean hands to minimise the risk of bacteria to the access site.
(Renal Unit), doesn't it? Not committed to it at home - doing the bag, that's the reason how he got sick, they said. "That's how it ended up blocking inside the bag, that it wasn't able to flow properly", aye? Took (him) to the hospital, the doctor said that the bag was not useful anymore, so was switched over to dialysis (machine).\textsuperscript{116}

As mentioned earlier, one of the on-going issues between the couple was the idea of Efu returning back to home dialysis. Efu wanted a haemodialysis machine at home but Emo argued against it.

\begin{quote}
\textbf{Emo:} \ldots (Efū) wasn't happy, came back and (I) said that the nurses were there and it's their job to do the treatment! But they (Renal Unit) wanted to bring the machine home. I came back home and I sat thinking, thinking about how it started with the bag and how he wasn't prepared to do the bag properly, aye? And, even with the machine, I didn't want to bring it home, because - he wanted to bring it home, but I didn't want it in case he wasn't going to do his treatment properly again.\textsuperscript{117}
\end{quote}

She was reluctant to agree with him that the weekly cost for petrol to travel to the hospital was a reasonable justification to switch to home dialysis. But she feared that he would revert to short-cutting his dialysis and become sick again.\textsuperscript{118}

\begin{quote}
\textbf{Emo:} The other problem is petrol, that there's just too much money that goes on petrol, but going to the hospital is the most important thing! All I say back is [to Efū], “You know exactly what will happen if you bring that machine home!” But he always says, “It's a waste of money!”\textsuperscript{119}
\end{quote}

In spite of his wife’s concerns, ‘self-responsibility’ seems central to Efu’s personal philosophy of being well and keeping on top of his CKD. His mantra of: “never give in to the disease” (\textit{e le fa’atu’u i le ma’i}) was his unique way of countering the onset of emotional depression and internalized anger that dialysis patients can often experience.

\begin{quote}
\textbf{Efū:} From the time I got sick with this disease, I am really angry, in my heart right? That’s why, I do my chores, I don’t want to be complacent or to give in to this disease, right? I’m angry, you know, because I want to fight it (\textit{finau}), and that’s why I go and do my chores and things like that.
\end{quote}

\textsuperscript{116} Samoan Translation: Emo: “Lea luma o iina foi sa tūu uma ai a, o iina foi vai ai lana tofitiga. Ua alu alu a le faiga o tofitiga ele faamaoni ia I le fale le igoa lea alu I luga o Soifua Maloloina a? le faamaoni le fale ile faiga ole taga pei ole mafutaga lena na alai na mai, vai ma mai faapaena na iua a lea ina poloka loa le taga ua le mafai na toe soloa dei lei a? ave loa la’a lea ile faamai vai mai loa le fomai ua le toe aoga le taga, ae ia a sui loa a? le dialysis.”

\textsuperscript{117} Samoan Translation: Emo: “I sau le faafia ai sau fai atu o galuega na teine fomai e vai, ao latou a galuega a na - ia ae fai mai o lae taumafiai foi ilele e aumai i tua machine. Ou sau loa lea la’a ou nofo a ma’o mafauau au mafauau le amataga mai ole taga e le faamaoni ia.”

\textsuperscript{118} At the time of interview, Efū was travelling from the Hutt Valley to Porirua (60km return each trip X 3 days per week, 180 km in total).

\textsuperscript{119} Samoan Translation: Emo: “Le isi mea e popole ile penisini, e tele le tupe e alu ile penisini, ae taūa le [alu ile falem’ai] – pau a ole tala le ga e vai i ai, "Eiloa, e iai le mea e tupu pe a aumai le masini mai le falem’ai", (Efū) faimai "E ma’i’mau le tupe.”
In Samoa Efu was always healthy and fit, fulfilling many of the tough physical chores at the “back of house” expected of Samoan men such as preparing food and fire for an umu pit (earth oven) whenever the village met.

**Efu:** There’s times when things happen at my Church, and I help with putting together the umu for the Church. Many times the Church people will come and the wood has already been cut and stacked, the stones and rocks are piled up ready for the umu, the pigs prepared, everything, done! I’m not a person to just surrender to this.

He was proud of the work he used to do on construction building sites and it reminded him and motivated him to keep active.

**Efu:** … we went up north…we were paid for the work with families, a? Underneath houses, also high buildings, low ones and other buildings had to lay flat right underneath and then crawl right below!\(^{120}\)

As depicted in Efu’s photographs, keeping busy and active is important for warding off self-apathy and the over-reliance on others.

**Efu:** That’s just the way I am, a? I try it out myself, no matter what’s causing it (pause), it’s different for those of us up here, a? They look at me and see that I’m strong. Some days after the machine, I come, wherever we have to go to do the shopping, or whatever else we might do, I know how busy it gets, but I come, and I’m still very well. But other people, after (treatment) they are very, very weak, and all they do is sleep. I don’t know what it is, I come back no matter what, and then I say, “The problem is, that you are giving in to the disease!”\(^{121}\)

When his wife Emo reduced her hours at work to be at home more, Efu made a conscious decision to be proactive with his health and to reduce the burden of care on his wife. They both liked to spend a lot of time in the garden and he in the garage workshop.

**Efu:** Emo used to work, a? She (Emo) resigned from her job...when I looked at it, it did seem that Emo’s here because I’m not mobile… that Emo does everything for me, in other words it must mean that I must

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120 Samoan Translation: Efu: Ia alae ala na ua ou ma’i I le ma’i lenei, o a’u e ita fo’i gale lai lo’u loto, a? Mea na e alai ona o’u alu fai a’u fe’au te le mana’o fo’i gale ou te fa’a fiftifmu po’o oute fa’atu’utu’u I le ma’i, a? E, e ou te ita fo’i le gale ou te mana’o a’u ia te finau fo’i gale aga’lai, le mea le na ou te alu ai e fai fe’au ma mea uma, fo’i la e iai fo’i taimi e iai ia, ia mea le au lotu, ia pe tapega se suavai a le au lotu, ia, tele a taimi e o atu le aulotu, uma tata fafifile, ululu ogaumu pe o faiga uma mea o pua’a, mea uma, e fa’i uma, o a’u fo’i e le’o se tagata fa’aapea oute fa’atu’utu’u a i le mea nei.

121 Samoan Translation: Efu  Matou o luga, ole mea lena lea e iai nei, ae, e fai totogi fo’i gae galuega aiga a? Tu ialo le fale, ia o isi fale e maluluga, ia lalo, ia a’o isi fale tallyua a’e a I lalo, ia, e mau I lalo e....
be very sick, true, there are chores that can’t be done, but, I try to be active and do things. That’s why as I said before, I’m very angry, I’m angry at the disease, fight it, I don’t rest!  

Interestingly during our interview, Emo made references in relation to her photographs in the ‘third person’. She ascribed to the ordinary social roles of family life where as ‘mother’ she kept the house warm and fire embers burning. Home dialysis would change the dynamics of the ‘family’ routine and potentially cause disharmony to these roles. Doctors are responsible for the dialysis routine; mother and father are responsible for the family and the children.

Samoan Translation: Efu O Emo sa faigaluega, a? Na la na fa’amavae ma lana galuega...oute tilotilo iai o lona uiga la a fa’sapea la e sau Emo ona ou fa’aatu’tu’u loa lea i le nofo ...o Emo e faia uma fe’au mo a’u, ia o lona uiga ua ou...ma’i tele, ia fo’i gale, mo’i, a o e lai fe’au e le faias, ia as ou te taumafai a a’u ia cute galue ma gaioi. Pei la ole mea na oute fai atu ai, o a’u ese lo’u ita, oute ita fo’i gale ile ma’i, finau, lei ona ou le malolo...
Emo: So, like many other times, is standing in the kitchen cooking for the father of the family and the children (giggling). … father comes home when he’s finished his … and, then the mother has just sat down, is the last to eat, yes, all the photos are the same! … (Laughing).

5.4.5 Two separate places

Uso’s family established a permanent dialysis base at the ‘family house’ so that he could continue living independently at his flat where he lived with his friends.

His parents refurbished two rooms upstairs by making one into Uso’s treatment room and the other for storing dialysis supplies. Every month 13 to 14 boxes got delivered to the house and then carried upstairs for Uso’s use. There were initial problems when the haemodialysis machine was installed because water that came from a stream close to the house needed to have the reticulation level adjusted correctly.

Most importantly, Uso’s mother Uga was happy that there was enough space at home for her son’s dialysis.

Uga: … I guess if we hadn’t have had that storage space it would be stored down here under the stairs, which, would be fine, probably just not as convenient as where it is. Though it’s well located … when he goes into his dialysis room, he’ll have a certain amount of gear in there ready to go. So I suppose it’s fortunate in a way that the house had enough bedrooms so that he could have a room.

Haemodialysis sessions last for five hours and so his parents wanted to ensure that Uso had access to the important appliances and comforts such as TV, Playstation and the telephone (Photos 7.23 and 7.24 below).

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123 Samoan Translation: Emo: Fo’i mai ga le tamā ua uma laga, ia, ae faatu’aluatu ai loa le tinā mulimuli e ai (giggling), e a ata ole mea tasi! (laughing); R Manaia.

124 This was partly because of the semi-rural location of the house and the distance between the house and the nearby stream which was the family’s main source and supply. A “special pump” was installed to ensure that the “700 litres” of water required for every dialysis session could be adequately pumped up to the second level of the house where Uso’s dialysis machine was installed. Further work was also done to resolve issues with the disposal of waste water through the “septic tank.”
Uga: He’s got it well set up, ‘cause it was the office… he’ll actually have two phone lines going when he’s up there. He’ll take the cordless from our home phone, so he can answer the phone up there if he wants to or ring out and ask me to bring home lunch.

Photo 5.21 Uga’s photo of Darlick The Good Monster

At home, Uga nicknamed her son’s haemodialysis machine “The Good Monster”, after a popular science-fiction television series. It was her way of acknowledging the importance that home dialysis had made to his and their family’s recovery.

Uga: A Darlick, (laughs) out of um, Dr. Who, you remember the Darlicks, the robots?… but my name for the machine is the Good Monster, ‘cause it is a bit of a monster, but it’s doing a good job (giggles).

It had been difficult coming to terms with his son’s CKD but since he started dialysing at home, it was good to know that he was there and not “stuck at the hospital”. He admitted openly that he deliberately avoided watching his son setting up his dialysis routine.

Usu: Clearing throat, sniffs) I really, I really appreciate that he’s able to dialyse at home, ‘cause it helps me to cope with it better, seeing what he has to actually go through. I haven’t seen him, in, you know, connect everything up yet…I don’t want to see him, you know, I’ll go up there when he’s connected, but, I don’t like seeing him, you know, putting all that stuff in… (sighs).

The family home provided a stable environment for dialysis and so Uso it was unlikely that he would have to relocate his machine to another house in the near future.
Uga: The machine’s set up here, in case the guys in the flat all decide to go in their different ways, and um, it’s easier to have it set up here, and won’t be any cost involved with having to move the machine.

Photo 5.22 Uga’s photo of her son on the dialysis

Uso realised that he was fortunate about being able to have two separate places to live and dialyse, when compared to his colleagues at the renal unit.

Uso: Ah, maybe not [just] Polynesian families, maybe just with most families as well, probably wouldn’t have the option of having the machine in two different houses. Like, that would be a bit different as well. I don’t know if I’d like it that much if I had it at my flat, I don’t think it’d work out as well.

Ufi, Uso’s sister, felt relieved that her brother agreed to dialyse at the family house where it was clean; unlike the flat where it “smelled funny”.

Ufi: Well they’re boys and boys are gross! (Giggles)...I think it’s nicer that he does it here (dialysis). Yeah, yeah, I’m glad that he can do it here, and it’s nice having him here, more… ‘cause it was hard, cause he was at home most of the time (teary), don’t wanna cry (anxious laugh, big breath).

Photo 5.23 Ufi of brother playing X Box while dialysing at home

His mother described the flat as having no “floor space” because it was often littered with “clothes, bike gear, helmets and empty coke bottles”. At the family home they
knew that he could maintain a sterile environment for dialysis and that he could stay there indefinitely to recuperate.

Photo 5.24 Uga’s son with dog relaxing at home

**Uga:** I don’t know, I honestly don’t know. I don’t know if I’d been overly comfortable if it had been at the flat, ’cause their whole standard of hygiene is, just, boy flat stuff, boy flat level.

Uso’s grandfather had a dislike of needles generally but shared Uso’s “fascination of the medical technology”.

**Uga:** But my father who’s quite squeamish really, he was like (laughs), he said to me aside from Uso, “I don’t really want to see Uso putting any needles into his arm.” (Laughs). So we…didn’t go upstairs till Uso was actually on the machine. And, and doesn’t look quite so gruesome at that point…

An aspect of home dialysis that Uso was concerned about was patient isolation at home. Some patients spent a lot of time on the telephone whenever they dialysed; others relied on family members to keep them company.

**Uso:** A lot of people, I know like le said, she talks to people on the phone all the time when she’s at home. Or ( ) the same, talk to people quite a bit, so, its, yeah, that would be easier talking to someone at hospital.

Based on his experience, Uso felt that patients were reluctant to ask questions about the haemodialysis machine. He wondered how the training could be improved at Margaret Stewart House so that patients found it easier to learn the complexities involved in managing their health, nutrition and blood levels.

**Uso:** One guy, ah, ( ) was in there... he’d actually finished his training, and he was there after hours, he couldn’t understand how to set his TMP, I mean, I could show him how to do it, but ah, I don’t, I don’t think he
understood how to change the alarm limits, and he couldn’t figure out why the alarm was going off, but um, yeah, I think, that was probably the same thing, he probably just needed to ask a bit more, so he could understand.

5.4.6 Transition from peritoneal dialysis to palliative care

Presented in this section are the photographs that Osi and Ofe produced about the special furniture and equipment that was used for their mother’s personal care. And some of the barriers of the built environment which obstructed their ability to carry out the tasks of care at home. Osi spoke about how it was an important time for her to be with her mother (Photos 5.25 to 5.28)

Osi: It was like 10 o’clock put her on the commode and it was like clockwork…and then bathe her and then change her and then… so I enjoyed it, because I enjoyed, like putting my Mum on the wheel chair, ‘cause I’d go, okay, “Put your arms around Mum and I’ll lift you”, and so I’d lift her and it was really nice because I’d go, “Okay Mum don’t worry I’ve got you, don’t worry you’re not going to fall, I’ve got you.” So it was nice to have that…

R: That closeness.

Osi: Yeah, yeah.

Photo 5.25 Equipment at home for palliative care

Photo 5.26 Saline bag

Photo 5.27 Bed table

Photo 5.28 Electric bed
Their mother had dialysed at home for 11 years so when they took charge of caring for her, they took charge of her CAPD. This involved the onerous task of unpacking and reorganising the numerous boxes of dialysis disposables such as sterilised gauzes, dialysis bags, tubes, sanitary napkins and dialysate solution. For as long as they could remember, these boxes were always “part of the furniture” this caused an overwhelming sense of sadness and admiration for their mother’s perseverance on home dialysis.

*Ofe:* For instance all her boxes would be up here, not big boxes, ah, but and all her syringes would be like, on this side. Just amazing, that um (sniff, tearful) - seeing all the medication that she had to take, and then keeping tabs of them um. Hence, you got that medicine, weekly thing, that little pill-case…so Mum had to be on top of them, you know…in regards to her bags…had to do them four times a day, but if you like missed a bag for one time, then you can account for it the next day, by adjusting the volumes.

Boxes were stored in the kitchen and flowed into the bedrooms (Photos 5.29 and 5.30).

*Osi:* I was kind of, “No, they’ve sent the wrong nappies again, we’re gonna put them in the box.” And you know, it was like frustration as well…that’s when my Mum…going, like quite messy. It was like, “No, no, big ones!”…then my Dad would go crazy ‘cause it was like, “Oh, the box!” and we’d just tatala (open) all the pusa (boxes) and then when my Mum was able to control it; like, just at 10 o’clock every morning, we realised, “Oh maybe we need a smaller size?” …So that’s how it was, that’s how it was done, but they…Ofe and Dad would look at me like, you know, you make the call!
There were more than 30 boxes that lined the wall at any given time, but after their mother passed away, the boxes were permanently removed. Photos 5.32 to 5.34 show the reclaimed empty wall spaces at the house.

Ofe: Yeah, you know and this was the kitchen, so, ya just looking at a few photos back in the ol’ days, when Mum was obviously you know well and was still doing her bags. There was always the boxes in the background, so, yeah, you don’t realise, you know and me, and probably like, everyone else like Dad and Osi, once all that space was
you know, it was like when all the boxes went and we thought, gosh, where did all that space come from, you know.

Their mother’s missed presence at the kitchen table was reinforced by the missing boxes in the background (Photo 7.36).

![Empty dinner table](image)

Photo 5.35 Ofe’s photo of the empty dinner table – missing Mum's

**Ofe:** The kitchen (turning pages) (pause) um, yeah, when I was sitting here, cause um, every time we brought Mum in, that (pointing to end of table) was Mum’s end here…wheeling her chair in, um at the table. Most times we try doin’ it in her room, but, it was also, we didn’t want her to stay in the bed, you know 24/7 obviously we needed for her in case of sores and what not, we tried to as much as we could to get her out, onto the wheel chair (getting up, open back door to light a smoke).

Over time, they monitored their mother’s change in health which included her daily ablutions. Finding the right sanitary napkins to use, maintaining an inventory of the consumables, and knowing what to order difficult tasks. Their mother was always a restless sleeper and this was symptomatic of her medication and dialysis treatment. Ofe laughed about the repainted toilet and how his mother complained that it was too bright to look at in the night time.
Ofe: (turning album pages) Yeah, Mum was... keeps saying, “That we needed to fix up the toilet”. So I took it upon myself to...get the back done, cause it was getting quite rotty, sort of thing... so I painted it white, and then um, Mum said, “It'll be good to have another colour.” …'Cause I think I got my colours mixed up, I was meant to get lemon...then as I put this colour on, then I thought, “Oh, you're kidding me! It was like all orange!... I always try to make sure I close the toilet door, 'cause I'm sure she, um (Laughs aloud). I'm sure she looked in thinking, “(Big sigh). Ahhhh!” (Laughing).

The family grew increasingly concerned about safety zones at the house shown in Photos 5.37 and 5.38 at the front and anterior entrances Photo 5.39. Several inspections of the house by several agencies confirmed issues for wheel chair access, but nothing was done to help the family put together an emergency or evacuation plan.
Ofe: Obviously if something was to happen, I mean we would've no trouble if there were two of us, then we could lift Mum, you know up the (wheel) chair, up onto the access, then into the house, and likewise out. But, in terms of fire hazardous, and so forth, or like, if it was only Dad here, then it would've been really hard, um you know if something was to happen, if he needed to get out of the house, you know it would've been really hard.

The greatest concern for their mother was slippage in the bath. The two siblings and their elderly father took turns to lift their mother onto the shower seat, but because of the short showerhead, bathing was extremely difficult and uncomfortable.
Osi: (Photo album, turning page) Oh, oh, the, now that’s the bath in [at the family home], and my mother never had a bath, but she’d shower, and she couldn’t shower on her own because she’d always slip...I don’t know, something happened, like we’d put in her chair, and put the chair over the bath, but because the shower head was too short, it wasn’t ta’ilo (don’t know) yeah no, it was really... Yeah it was like she would go pale and it was like she couldn’t breath... yeah, so we stopped, and um, we said to Dad that, for him not to do it as well, ‘cause he was getting, it was quite an effort to put my Mum on when we were at work, yeah, so that’s our bath shower.

They enlisted the help of outside agency caregivers, but bathing was still a difficult and hazardous task of the care routine.

R: You and your Dad did hurt yourselves, with your backs?
Osi: Yeah, yeah, I think it was just the lifting from the wheel chair to the bed, to the commode, and things like that...It wasn’t till towards the end because it not only damaged, like my Dad and I had saw backs, and we were forever going. I was going to acupuncture and so forth, um, ttt, and, also not knowing, if we were hurting her (mother), here.
Showers became extremely tiring and exhausting for their mother because she lost a lot of physical strength and was unable to sit comfortably on the bath seat. It was then that the carers decided to abandon the shower routine for bed baths.

Osi: My Dad said that you know we weren’t to take her to the bath anymore…and so my Mum was sponge bath from March onwards, but, she’d always say, “Oh, please I, I need to take a bath.” And we’d go, “But we can’t Mum, you know what you’re like.”

Ofe said that he was overcome with grief for his mother whenever she pleaded for a shower. He empathised with her desire to bathe freely under fresh running water, an appreciation he understood that was part of her feminine care.

Ofe: But I think Osi might be able to give you more insight and that, so that’ll probably um, yeah so um (tearful, sniffing), yeah, but you know I think um, just as time went on and it, and…even though having a sponge bath, but you know just having a proper shower….it would’ve been um, you know sort of thing, so just really you know, my heart, I was just...(quiet, with feeling) even though it was something small, but you know, if something like that, you know, and probably more so, for, you know, for a fafine (woman) sort of thing, you know that would’ve been ideal to have, yeah, so (pause).

After their mother passed away, they wondered why no one had suggested they replace the bath with a wheel chair access shower. It would have been the most logical solution and would have resolved the difficulties they had with the bathing routine. However, back then, they were preoccupied with the care routine and an option that was never seriously explored.
Ofe: So we had this Palagi [caregiver] one come in, so she was quite good, she was um, yeah, she was quite a character but, the bathroom is the next one that I took photos of, um, ‘cause again in regards to the structure of the bathroom to make it easier, like grips, um….

5.4.7 Waste Disposal

A photograph of the street at the front of the family house shows where household rubbish was picked up weekly by local council rubbish collectors. Both Osi and Ofe talked about the high quantities of rubbish from dialysis. The refuse of empty dialysis bags sometimes reached up to 50 to 60 bags per week. On rubbish days they were worried about what their neighbours thought about them and felt ashamed of the ‘extra’ effort that the council workers had to do in loading up their rubbish bags.

Photo 5.42 Front street access where council rubbish collectors picked up dialysis waste

Osi: Actually having a proper bin, to put those pathetic empty bags…you know, open the bin and then, instead of getting the bags and, because my Dad would use whatever plastic bags, whatever grocery bags were there, so if there was a plastic grocery bag, you know it was just nanoa (tied), and I’m sure the guys, the Hutt City council guys who would come around to pick up the rubbish, “Gaww, here comes (address and street number) with their (grinning, pause)… yeah, here comes (address and street number)… was like that… and so it would’ve been really helpful to just empty it just in the bin, and it would’ve been really neat, to have it, an actual sink, to drain, the fluid, um, ttt, and um, in an ideal world, actually.

Undiscarded dialysis bags when left for weeks can produce a terrible odour and Osi and her father discovered this when they forgot to throw away a stack they stored at
the back shed. After this particular incident, they vowed to manage the rubbish more efficiently so that it never happened again.

Osi: And my Dad would clear up the bags, like you know all the emptied ones, they'd emptied, it was like um, he would empty it like how often they needed to be emptied, like um twice a week back in the shed… I remember we were busy with a family thing, and um, my Dad and I overlooked in emptying the bag… and it was so busy, and you know I’d sit there I’d go, “My gosh what’s that smell?” So I’d go in and tapena (tidy) all the, the shoes the next day and it was like, “Oh my gosh it’s still there”. And it didn’t dawn on me until the fourth day, I thought, “Oh, my gosh it’s my Mum’s bags we forgot to take them out!” So I said to Dad, “Oh, it was Mum’s bag.” And he would go, “Oh, talofae!” So we made it a point to always keep an eye out for it.

The purchase of council rubbish bags at the supermarket was $10 but because the family needed more than this each week, Ofè gathered as many supermarket plastic bags as an alternative. In the 11 years that their mother dialysed at home, they had had not been told whether the plastic bags could be placed in the recycle bins and so everything was put into the general rubbish.

Ofè: We’d have these plastic bags, Pak’N Save bags, I always make sure that when I went shopping I’ll just buy heaps of them, because, at the end of each of day… have about, probably about eight, nine bags, empty bags, so that they had to be obviously ti’ai (thrown away).

5.4.8 Extra laundry and water use

Both Ofè (n=2) and Osi (n=1) produced similar photographs of the washing machine and the laundry sink to highlight extra laundry and the repetitive work involved in CAPD and palliative renal care. Until they took over the work of replacing their mother’s dialysis bags, they had taken for granted how long she had been doing it for herself at home on her own without assistance or complaint. As shown below, the sister and brother duo made independent photographs of the laundry sink which was used to dispose the used dialysate solution of toxins and fluids from their mother’s dialysis. The sink was never used for washing or soaking clothes in and it was an issue which often worried Osi who wished that her mother could have had a separate ablutions area to use for dialysis.
Osi: That’s um, that’s the wash room... the fale tagamea (laundry). Back in the day, it was the other way around, the washing machine used to be here and the sink used to be there. (Pause) And then when they had extended the kitchen they changed the sink, so it was really difficult to get through there, to empty her bags... ‘Cause that used to be quite nice and clear that aluminium sorta look, yeah, but there’s only a small space to get through there, and we couldn’t soak our clothes, we have to use a bucket... We used to have this string here with the scissors, so we’d cut the tube and tautau (hang) the (dialysis) bag there, but it was odd, because we emptied the bags through there and yet did our tagamea (washing) there. But that was the only area, yeah, that was the only area we could do it in. Yeah, so that’s the sink.

5.4.9 Electrical appliances

5.4.9.1 Fear of household electrical appliances

The elderly patient Ata who was shown earlier as being resistant to home dialysis, did in fact express a genuine interest in having it at home but had to reject it because there was no one at home to help him. Although, Ata lived with his teenage grandchildren, he did not think it was appropriate to expect them to be responsible for
his dialysis or for his health. He also said that because he had a lot of extra space at home, dialysis would have been ideal for him.

Recently Ata’s HNZC home was renovated and nearly half of all of Ata’s photographs were of the open views and hills that surrounded his house (Photo 5.45). It was obvious that he derived a lot of pride in his house and found pleasure in the natural wood panels that lined the corridor and sitting room, a feature of the older styled HNZC houses (Photo 5.46).

Ata enjoyed being able to sit on his days off from dialysis and look out into the expansiveness of the greenery outside (Photo 7.46). The new renovations had given him a new door (north facing) and greatly improved the amount of natural light that streamed into the kitchen/dining room. Before this, he had only a small window view (east facing) above the kitchen sink. The new changes gave Ata a renewed sense and appreciation of his home, so much so that he even contemplated taking up home dialysis. Renal staff tried often to encourage him to take up home haemodialysis, but none of them could reassure him that his cardiac heart pacer would be safeguarded and protected from potential electrical hazards. Ata pointed to the photograph of the electrical appliances in his kitchen which his doctor warned could cause electrical interference to his heart pacer (pictured in Photo 7.48).

125 CAPD can require the use of the microwave from four to six times daily to warm dialysate solution prior to treatment.
Ata’s concern about the microwave interfering with his heart pace maker

Ata: They were really trying to encourage me to come and learn how to operate my machine – well, I can do my own needles (blood levels), but I told them, “I will not try even to do one thing! Because, the doctor told me that the pace maker that I’ve got, that I’m not allowed to handle any electrical machines; including the microwave and the fridge, said not to touch these too long.”

5.4.9.2 Microwave

One of the frequent expressions that he made during our interview was: “My heart going out to Mum” (n=4). It reflects Ofe’s deep respect and awe of his mother’s enduring strength and commitment on home dialysis. Ofe made photographs of the household microwave (Photo 5.48) because it was used at least four times a day to warm up her dialysate bags.

Ofe: She just made sure that what she did, she would never burden anyone else (holding back emotion) and, just yeah, probably just my heart went out to her... Mum was doing this for the past how many years... she might go, “Go warm up my bags in the microwave, and get this and that”, which was no, no problem... it wasn’t until, you know, last year, I started doing it on a regular basis...I just take my hat off to Mum, you know (fiddling with album) for doing this for all these years.

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126 Samoan Translation: Ata E fai le bag. La foi e tauanau a’u fai mai oute alu atu foi lele e fai a e au lau masini ma e line le masini ma ou alu atu i o (Margaret Stewart Home Training Unit). Aua ute nofo a au ma ta tui iai nila foi nae. Ou fai atu “Oute le try ina a se mea e tasi! Aua, ole upu ole fomai ia au ole pace maker lea ia te au ise faasā ia au ona ou tago i masini ia na e oo foi la ile mea lea ole microwave ma le mea lea ole fridge, fai la aua ute tago umi foi lea lai.” La uma a la ona ou fa’amataia ia ( ) ia mea, ia ae oo foi ananafi ou alu atu ae tuli mai foi au i lalo ile Margaret Stewart foi lele oute sau.
Below, another Photo 5.49 of the microwave and its location in the kitchen that Osi produced. The one in the picture was the family’s second microwave, bought through her mother’s sickness and disability benefit for the purposes of her dialysis.

Photo 5.49 Osi’s photo of the microwave

Osi: And it was um, funny cause Ofe got her a microwave in 1989, and, but that was way before my mother went on dialysis, and that’s where we used fa’amafanafana le mea’ai (warm up the food) and one day the microwave blew, and my Mum was on the dialysis at that time, and they managed to go to Social Welfare and get a microwave under, yeah, under a certain scheme… but it was so high, up where the microwave was, we either did it or she tip toed to try and get it, yeah and it was always three and a half minutes, yeah make sure that the tube was facing up, yeah, so the microwave was very important… so, my Mum and Dad pretty good that they got one through the Department of Social Welfare…

5.4.10 Cold house even with insulation

One of the main difficulties of providing care for someone at home who has a chronic illness is ensuring that there is adequate warmth in the house. Osi’s family had their family house insulated through a local Iwi home energy programme; however, because of its older condition and size, it was harder to maintain indoor warmth (Photo 5.50).
Osi: …there’s a lot of condensation, so when the windows are weeping it’s quite cold and damp. So, it would’ve been really helpful if there was a dehumidifier, to get rid of… I don’t know what kind of heating, ‘cause we had it insulated a couple of years ago, properly relook at actually getting actual pink bats in, um, ttt, if, we could do it all over again, um… I think it was just the walls and underneath. It helped (insulation)… it still needed a bit more, because it’s a lot older.

The warmest room of the house was the sitting room where they kept a heater (Photo 5.51). Osi and Ofe found it difficult to keep the oil heaters on for any length of time without their parents noticing. Like many elderly people, their parents were always worried that using the heaters to warm the house would increase their electricity bills.

Osi: We’ll take Mum in, turn the heater on, turn the TV on, depending on what she wants.
In Photo 5.52, Osi made a photo of the framed photograph of her mother dressed in her warm woollen hat, jersey and gloves. It was taken by her brother when her mother had just finished showering. The photo was a reminder of her mother’s vulnerability against the cold frosty Wellington weather and how difficult it was for them to keep her mother warm.

![Photo 5.52 Osi’s gift from her brother and a story about Cold](image)

Osi

…Me and my Mum, yeah, can’t see it, but, my Mum’s actually smiling, but it was like, it was the bed socks, and then the gloves... but it was quite difficult to try and get her hands through the gloves, because they had stiffened up, so, we had to (enacting rubbing hands) like this, then came the beanie, then the scarf... (long pause) but you know, like, when I go through winter, ‘cause this was a cold winter, I just think, I thank the lord that she’s not here, ‘cause it was really bitter, and she would feel the cold, you know old people really the cold... and we’d get the heater going, but, they’re conscious of the meter...the heater giving her headaches, and so forth...this year when it was really cold, I oh, thank the lord she’s not here to feel it, yeah.

Although Ata did not take up home dialysis, he made a photograph of the wind chime (Photo 5.53) hanging in the outside veranda and the oil column heater (Photo 5.54). It captured his concerns about coming home on cold days after his dialysis session at the hospital and struggling to get warm. This has relevance for nearly all of the dialysis families where participants described the treacherous winds and cold of Wellington’s weather. In Chapter 3 the Tuaoloa wind\(^{127}\) was described as one of the most treacherous winds because of its extreme coldness that can fatally impact on the health of the elderly.\(^{128}\)

\(^{127}\) Key Informant Interview: Tuitama, “E mama'i ai tagata, ae malolosi ai manu,; “People become sick, the animal stronger”. “Ae agi le tuaoloa – e matu'ai malōlo”. When the Tuaoloa blows – it is very, very cold”.

\(^{128}\) Ibid. Stories of the Tuaoloa having led to the deaths of elderly people when it hit the southern region of Samoa in Aliepata.
Ata: It’s lovely during the day in summer but when it gets to Winter, oh, well then it comes mostly from the Southerly, it’s terrible!\textsuperscript{129}

5.4.11 Summary

In this section, families described how they adapted their homes for dialysis treatment. An aspect that is often taken for granted is the additional use of household space, electrical appliances, as well as extra water and electricity required for dialysis. An unexpected consequence of the building renovations was the onset of fuel debt and dialysis equipment shutting off while in use. Fears of using heaters were also experienced by most of the elderly participants whose concerns about high electricity costs took priority over the importance of indoor warmth as a protective measure for their health and wellbeing.

For younger patients, home dialysis provided the independence and freedom of being able to go flatting, work and study. However, during periods of illness, the lack of space for storage supplies and the added concerns about maintaining a sterile

\textsuperscript{129} Samoan Translation: Ata: “Manaia ia aso ole summer, ae a o'o nei la ile winter ia aua 'e feagai tonu lave ma le southerly, it's terrible!”
treatment environment contributed to issues of stress and dissatisfaction with home dialysis.

*Taimasatō* is a very low tide that exposes the rocks and marine life to heat, wind and rain. It highlights the extreme difficulties patients have in trying to fulfil the day-to-day tasks at the back of house; tasks which are associated with their adherence of the dialysis routine.
Section C – Middle of House

5.5 House of Healing, House of Ashes, Va Taupia: The Middle of the House for Home Dialysis

“Ua matua apulu tofaga, taulia le fale efu”.

Table 5-8: Key Themes: Section C – Middle of House

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In this chapter, elderly Samoan participants have eloquently and metaphorically described the family home as an important dwelling or refuge. The metaphors apulu tofaga (to shed in place), fale efu (house of ashes) and ufiufi o manu gase (protection of a wounded bird) provide contextual meanings about the Samoan family built environment and the notion that the patient and carer dyad is intimately connected with ‘place’. In the first section, I discuss what these three metaphors mean. I then investigate the way in which Samoan families articulate culture in their everyday experiences and more specifically through their obligations to one another within the dyadic relationship of ‘patient and carer’. Families have conscientiously and creatively described the interior spaces of their homes with many rich and diverse themes that reflect their deep understanding of matters related to being able to

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130 Samoan Translation: You know Ramona, O upu ole gagana a Samoa, lau te fa’amatala maia foi ia mafuaga le mea na tupu, gasegase se aito, pio se faletua, there’s such words as, “Apulu Tofaga, Aulua le Fala”. Mafua mai la ona ole umi o faataoto seisi, le ma’a a? Pei ua “apulupulua fala”, “sau aie le apulupulu”. Sia lea le ata le na e aumai ai upu e fai le alofa ile tagata ma’ai. I think that’s where exactly he’s coming from, his matai title is less important in some respects, when compared to how to heal the sick. La oele a tau fa’amalamalama ile tamatai lea aua e pei ole tatou gagana a mafuaga o upu mea faapena a, le alofa, le cokia le umi ona faataoto liia seisi o o mai foi ia masalo a, mea na feagaie nei ma Faisea ole matuai umi le taim a? la ona o tatou foi o faamanu, fieai ma a se ana faapea e ta’alo pei i fala, mea masani ai maua mai ai nei upu “Ua matua apulu tofaga, taulia le fale efu”.

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maintain wellness, spirituality and manage the complicated issues of death and illness. Figure 5.3 (below) summarises the roles of ‘carer’ and ‘patient’ and their corresponding cultural capital; their associated anatomical symbols at the right side of the house.

![The House of Ashes Diagram](image)

### Figure 5-3 The House of Ashes (Apulu tofaga) for long-term illness

#### 5.5.1 The shedding house and Samoan spirituality

At the start of an interview with an elderly male participant, my co-interviewer\textsuperscript{131} greeted Olo by referring to the family home as *fale efu* “a house of ashes”. This was a respectful way of formally acknowledging Olo’s role as a carer for his wife until she passed away.

\textsuperscript{131} Lavea Tupuola was the name of my co-interviewer, he was also my external cultural supervisor. As mentioned in the Methods chapter, I had the assistance of my cultural supervisor to interview two of my elderly male participants. Ata (Family 1) and Olo (Family 3) to encourage a male/gender perspective in relation to the topics around caring roles and chiefly roles. Lavea has expertise as an orator as well which would enhance the discussion with participants that I would not have been able to do as an interviewer.
Tupuola: You know Ramona, the Samoan proverb when a Matai or his wife is sick, “Apulu tofaga. Aulia le Fala.” It originates from a person being ill and lying down for a very long time. It’s to acknowledge the love and the enduring difficulty in the care of a sick person. I think that’s where exactly he’s [Olo] coming from. We’re like the birds of the air, we have the freedom to come and go, but, if we find ourselves restricted by illness, therefore on the fala (sleeping mats), then, there’s a saying, “Ua matua apulu tofaga, taulia le fale efu.

The first metaphor describes the specific physical site or tofaga where the human body undergoes the natural cycle of decomposition or apulu. The decomposition typically consists of human sweat, skin, medicinal oils, herbal plant rubbings and other waste products resulting from the processes of healing and illness. These would include the patient’s diabetes medication, dialysate solution and consumables. The photo of the schedule for medication and emergency numbers line the wall; in the far corner is the cabinet with medicine bottles, lotions and sterilisers.
The second metaphor is associated to the place of convalescence where the patient physically and emotionally spends the most time: the *fala* ‘sleeping mat’ or bed.¹³²

The third metaphor likens the patient to an afflicted bird, unable to fly to the air and confined to its nest. Used this way, these metaphors are offered as a way of honouring and complimenting a carer’s in-depth propensity for compassion and devotion; it is and expression of empathy for the patient who is house bound.

Photo 5.58 is the only photograph that Ofe produced from his total collection of 72 photographs that was of a person. It is a photo of his mother lying peacefully in an automated hospital bed a few months before she passed away.

Photo 5.58 Mum, 12 months before she passed away

Ofe: If I was running a bit late waking up, and then she’ll just always yell out sorta thing, no it was quite funny, but, yeah but I think, early in the mornings… just standing at that door way, and just looking through that picture… know, (her) head is stood up sorta thing on the bed and just having her just wave out you - that got me through the day sorta thing. But you know as time went closer, she would just have her eyes closed…you know it was just getting hard... hard for her.

Photo 5.59 her mother’s favourite bed quilts are important household objects which illicit strong memories of love and care.

¹³² Supervision, Lavea Tupuola Malifa, date: The complimentary and dyadic relationship between a carer and a family member's experience of long-term illness is found in the following two metaphoric references. 1) "Ufiufi o manu gase" (The protective covering of an afflicted bird). The first reference denotes and emphasises illness as experienced by a small and helpless animal or creature of the natural environment; the response of protection is a unifying and ethical response. *Ufiufi* (covering, concealed) an ailing or sick (gase) bird (patient, family member) figuratively is carefully tended. In the second reference, *apulu tofaga* the physical site and place of illness gives context to the activity of human deterioration, illness and carer attendance. 2) "Efua matua'i apulu lava tofaga, aulia le fala, tauila le fale efu", (Ashes, dust, rubbings, perspired, sweaty, chaffing; from chronic, endured, prolonged, complete, deposited, covering, falling to the mat and sleeping place; hence the arrival and entry into the house of ashes). The second reference maximises the stark yet mundane phenomena of the human body undergoing gradual biological deterioration within two distinct physical locations: a) the personal items or objects used for rest and sleep (bedding or mat); b) the dwelling or built environment used to shelter and house the unwell family member as well as the attendant carers and visitors.
Osi: Oh, deary me, I should have tidied this one here, before I took the photo, but that’s the couch, um, my mother always, when she did her dialysis, like if she was running late with her dialysis, at about 10 o’clock would be her last one, so we’d all go to sleep, but she’ll be up on the couch at home doing her dialysis and watching the TV, and having her late snack…When she’d come here, she never like sleeping in the spare room, she always wanted to sleep in here, so we’d always, you know, do the couch properly.

5.5.1.1 Mirrors connect the waking and sleeping worlds

Within the central area of the traditional Samoan house, light from the fire hearth (magalafu) was lit in observance of Va Tapuia or prayers as part of the healing and protection of those within the family who were unwell, vulnerable and dying.

This adds to the multivalent aspects of the fale efu as a metaphor of the built environment, conveyed especially by the interior walls that Ofe paid particular attention to. Photo 5.60 is a close-up image of a beautifully carved relief of the ceiling architrave, in his mother’s bedroom. He imagined that this wooden panel of vine and fruits provided both comfort and interest as she lay on her bed. His parents bought the house four decades ago in an old industrial area of the Hutt Valley. It is a unique feature that shows off the innate craftsmanship of a house that would have been built in the early 1940s.
Photo 5.60 Wooden relief of ceiling architrave in Mum

Ofe: For whatever reason I took close ups of the edges of the wall of this [architrave], um you know maybe when Mum was um, like she wouldn’t have, not staying in the room a hundred percent of the time, but, possibly when she was just lying there, she would’ve just been um staring at different things that would’ve been in the room… yeah, but I (deep breath, sigh), yeah, for whatever reason, I just captured that um, just the shapes and the, on top of the ceilings (pause).

Ofe also focussed on the how different rooms reflected different shades of light in the house. Photo 5.61 is the window view from the living room taken as a reminder when his mother still had some mobility and sat in her wheel chair as she watched him leave for work in the mornings.

Photo 5.61 Mum’s view from the window

Ofe: Yeah, looking out, and then every time I came in, um, like I’ll just see Mum, she’d just be looking out the window, oh, I don’t know what’s going through her head, or what her thoughts are, ah, or whether because she was stationed that way...That’s why we moved Mum around the house (turning album pages). That was just pictures of the sitting room and the corners where we used to put Mum… she would just stare out the [window] this was always when she was in the wheel chair, she’d just be staring out the window (pause).
The solitary line of light shown in Photos 5.62 and 5.63 is reminiscent of the single blind (*pola*), that, when left undrawn in a traditional Samoan *fale* is believed to form a way of entry and exit for the spirits (mentioned earlier in Chapter 3).

![Photo 5.62 Shades of light from Mum's window](image1)

![Photo 5.63 Single entrance and exit](image2)

Becoming more aware of their mother’s frailty, he made images portraying her heightened spiritual awareness, particularly the times when she started noticing ‘visitors’ in the night time standing by the wardrobe mirrors and near her bed. Despite the family’s practice of covering all the mirror furnishings at night, they validated and acknowledged their mother’s waking and sleeping states of consciousness. These phenomena are commonly associated with chronic illness and death events, and Samoan families often link these to Samoan mythological and cultural knowledge.

The bedroom lamp (Photo 5.64) elicits a story about the night-time movements in the house.

![Photo 5.64 Mum’s lamp](image3)
Ofe: ...that was her lamp that we turned on at night time, that was Mum’s um, yeah, it was sad that time, ’cause she kept on, she’ll call out and we’ll walk in, and she’ll go that there was someone staring at her (from the wardrobe), we always had this closed, we always had an i.e. (sheet/blanket) over it.

Photo 5.65 Open door mirror in daylight

Photo 5.66 Covered door mirror at night

Photo 5.65 shows the wardrobe mirror in the day time with the wheelchair’s reflection. At night time, the same mirror is covered up by a curtain (Photo 5.66 and 6.57). As their mother drew closer to the end, the visitations grew in number.

Ofe: Oh yeah, like um (sniffing, tearful)... the next morning, when I’d come in and get things ready for her bags and her breakfast...and open the curtains, and then she’ll just say, like “Oh,” you know, “there was someone here in the room last night.” And then, the first time I heard it, but then, you know she was telling Dad I think too, and Osi, and then she’ll say, “Oh, you know there was someone”. I say, “Oh who was it?” And she goes, “Oh, I don’t know”. You know, it was like there was someone there looking over her, um, yeah, yeah, so, and I just say to her, “Were you scared?” And she’ll go, “No”. But, like Mum wasn’t scared or anything, but this was always closed, um in regards to having an ie (sheet) over that (mirror), yes (looking through photos, reflective).
Photo 5.67 Mirrored chest of drawers with draped quilt covering at night time.

5.5.1.2 Clocks for connecting the present, past and future

The traditional Samoan house of ashes is accepted by families as a built environment for multiple purposes of providing a place for convalescence; for the preparation of spiritual departure and the end of physical life. Time inside of a dialysis household is seen very differently and participants produced photographs to capture ways in which household clocks provided meaning, purpose and obligation to their medical routines and their family commitments at home. Photo 5.68 of the kitchen windowsill clock captured Usi’s feelings of sadness for her brother’s long and gruelling hours on haemodialysis.

Ufi: That was meant to be of the clock, just like, how much time it (dialysis) takes up, yeah.
Osi’s mother had a clock (Photo 5.69) in every room as a reassurance of keeping her next session or exchange on peritoneal dialysis. In the past, clocks had represented “broken sleep” and years of her mother working on night-shift to support the family. Now they were an essential part of keeping her alive.

Osi: … I took a photo of this clock. Um, because, this clock used to be at my Mum and Dad’s house, and my Mum always loved um knowing what the time was. So she’d (emotional, clears throat) always look, and I think it was to time herself how long it would take to do her bag, or what time the news was on, ‘cause she wanted to know what the weather was like, so she could hang out her washing the next day, ttt (pause). Yeah, so, everywhere in her room she’d have a clock, be it a digital, an alarm clock, um or this other, a couple of clocks, it was like everywhere you went around the house there was a clock (crying)… oops! I just have to get a tissue (clears throat and goes other room for tissues, and returns).

A clock was given prominent position next to Ata’s wedding photo on the mantel piece in his bedroom (Photo 5.70).
Time can stand still even for household pets when a loved one is on dialysis. A photo of Oscar, the family dog, outside the treatment room at home.

![Photo of Oscar](image)

Photo 5.71 Even the dog waits during dialysis!

**Uga:** The door here is the dialysis room and the dog knows, that he’s not allowed to put his nose in, so he’s quietly waiting out there. Normally, if Uso’s dialysing at home here, and no one else is home, the dog is actually tied up outside, he wouldn’t normally be in the house. But, here, obviously I was home, so the dog’s off the leash, sitting there waiting for Uso to come out.

Home is a better place than the hospital for ‘waiting’ and ‘spending time’.

**Usu:** Whether rightly or wrongly, we think, it’s better for him [Uso, his son] and better for the family as well. You know when they pass on, you want them to be at home [dialysing]...rather than stuck in hospital....home’s home, yeah.

Taking care of his dog strongly correlated with Uso’s own self-care. Photo of family dog (Uso n=1, Uga n=2).

![Photo of family dog](image)

Photo 5.72 My best friend, my dog

**Uso:** And my um, my dog ( ) he’s, well, I suppose he’s pretty good, he’s a man’s best friend!

**R:** (laughs)

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133 Psedonym in place of original name.
Uso: He’s always, ah, he’s just always around with me, and he always reminding me. I suppose I always have to take him for walks, or just run him up in the driveway when I go in the car (laughs)….Yeah, but um, I suppose I put him in, it's because he’s good to have around, he’s good to remember, remind me to keep exercising and to keep going…

5.5.1.3 The important role of church social networks

Families social support were often drawn from their church networks. While the earlier section highlighted the indigenous metaphors from Samoan culture, they coexisted alongside Christian values. In this section, participants talk about their spiritual faith in God as an important source of help in response to grief and loss, and the restoration of hope, identity and wellbeing.

Bible reading and praying regularly for spiritual guidance was important for most of the participants. Early morning prayers with her mother was a daily ritual which began when Osi was a young child (Photo 5.73).

![Photo 5.73 Tusi Paia, Holy Bible](image)

Osi: That one’s the Tusi Paia (Holy Bible…but, nah she like, every other Pacific Islander person from Samoa, I could be wrong, but every morning at 6 o’clock without fail, when she was really, really strong back in the ‘90s, she’d wake up… she would sing, and then she would pray, and then she’ll read the bible, and it was really funny because as soon as she said, “Amen”; if I was still asleep, you know she would just hit me on the head, says, “Oi! You can hear me praying and let te moe! (You carry on sleeping)!” I thought, “Ohhh!…” she of course enjoyed going to church, and because my grandfather was a faife’au (church minister)… my mother knew the bible.

Ufi’s bible (Photo 5.74) lies open on her bed and she sought privacy in her room to find inspiration from it every day. In the picture, hanging in the background, is a Samoan ie toga fine mat; a gift from her grandmother’s funeral and Ufi acknowledged it as an important symbol of her Samoan identity and heritage that she wanted to
learn more about in the future. *Toga* or fine mats are Samoan feminine wealth and used in highly ritualised ceremonial exchanges which are considered formally binding between families.

![Photo 5.74 Holy Bible and Granma's fine mat](image)

**Ufi:** *That one, Mum thought it was meant to be of my mat, but it was just meant to be of my bible...yeah, just getting into the Word and stuff.*

Ufi’s next photos of her church and her youth pastor (Photos 5.75 and 5.76), were taken to highlight the support she sought to help her to deal with the shocking news that her brother had contracted CKD and required dialysis to live.

![Photo 5.75 Spiritual support](image) ![Photo 5.76 Pastoral care](image)

### 5.5.1.4 Misunderstanding SKD and the curse of dialysis

Church was an important place where Ivi and her husband’s pastoral obligations gave them purpose and spiritual closeness to God. It was also a place where paradoxically she had to deal with her parishioners’ judgemental attitudes and beliefs that ‘her daughter’s CKD is a sign of God’s displeasure and punishment’.


Ivi: *I used to get really hurt, because even the church members, you know they used to say, “Oh, that’s the faifeau’s (pastor’s) daughter, but, why is she sick, she shouldn’t be sick, ‘cause, that’s the you know faifeau’s daughter!”*

R: *How do you cope with that?*

Ivi: *I just, oh, you know, I just ignore it and there’s a lot of people that left, um, only because I was straight up and I protect, you know, I protect my family and things and even some of them used to say, “Did you know that Jesus took all our sins and took everything at Calvary?” And I went, “Yes”, and then they kind of look, were pointing their finger. That my daughter had a condition and that should’ve already been taken away unless I’ve been cursed!*

Outside, Ivi’s work provided a calm atmosphere of family values, prayer and reflection that was difficult to find sometimes at home and church Photo 5.77 (above) and 5.78 at work (below).
Ivi: This photo here, is a picture of the quiet, is what we call the quiet room, where, if you’re feeling a little bit down, and you just need a place to go, and relax… at work, and this is another place where love to go before work … And just sit there and like just meditate or pray. And um, I like this statutes because they represent family…so that kind of calms me down, and gets me ready for the working hat (laughs)...I ask for um prayer and ask for protection over my kids while they’re at school, and my daughter while she’s dialysing (clears throat).

At church, Ie was the lead singer for the youth band and it was through music that she found solace and faith in God. During my interview with her, Ie spontaneously started to sing one of her favourite songs to demonstrate in the best way she could what music meant to her.

Ie: *(Starts singing confidently and clicking her fingers)* “Shout to the Lord, All the earth, That I sing, Power and majesty, Praise to the King, Mountains bow down, As the seas will roar, At the sound, of Your name*, yeah, that’s like…

R: Awesome!

Ie: One of the songs that I like, there’s a lot of songs, I think, music is like, it’s real, yeah, I really like, I love music, it’s like…

R: That inspires you?

Ie: Yeah, especially Christian music, like I’m really into that, there’s heaps of songs I like.

In an email she sent to me, Uga said, I find myself becoming more private about my faith but it is very much the bedrock of my life - vital and alive for me*. A quote form Acts 2, “I have pitched my tent in the land of hope” summed up her firm belief that “God provides love, protection and safety over her and those she loves”. Below, Photo 5.79 Uga with close friends of her church ‘home’ group.

![Photo 5.79 Close friends for support](image)

Uga: *(Back to album). Oh friends, I had to put photos of friends in…but, um, it’s, more than just having, meeting and having a coffee, the idea of it is, that we encourage each other in our lives wherever we’re at, and we’re awfully honest with each other. (Smiles)*
The formation of the Pacific protestant churches was Ata’s life’s work and he talked freely about the early pioneers who first arrived in Aotearoa during the 1950s and 1960s. The churches flourished to support families and to preserve and maintain cultural knowledge and traditions. Below Ata took Photos 5.80 of the framed photographs of church colleagues, who, like himself were the emerging Pacific leaders of the 1970s.

Photo 5.80 Founding church leaders

Ata: I was Secretary from that time up to ’89. It was 37 years I was Samoan secretary and the church Assistant Clerk. Even though my English was so broken I still did it! (Laughing) We were the first four elders of the church, myself, Setu Solomona, Vaeloto Teumanu and Ta’avao Aiono. They all passed away, only I [was] left and maybe lived on for the next fifty years or more.\textsuperscript{134}

\textsuperscript{134} Samoan Translation: Ata: Ou failautusi mai loa lea right up to ’89. Tusa e thirty- seven years ou failautusi Samoa ma le assistance clerk. Tiga na panupanu au nanu ae (talie).
Photo 5.81 is one of the church’s first women’s netball team which in the mid 1960s which produced many Pacific representative players the Wellington senior and New Zealand national teams.135

5.5.2 The major role of family members within the home dialysis built environment

The le Fa’atupu, Family Growth Fine Mat, Children symbolises the value of nurturing the children and descendants of a family. Children make an important contribution to the dialysis routine at home. Obedience and service to older family members are values that are taught to children at a young age and they are expected to contribute to the day-to-day tasks for the benefit and wellbeing of the family.

5.5.2.1 Children and their siblings

Ivi’s five children spent a lot of time at the hospital because of their older sister’s CKD.

R: What do your kids understand about Ie’s dialysis, her condition?

Ivi: They understand, how the kidney functions, um, my um, and they understand that, ‘cause she explains to them, they understand a lot and they understand that there’s times when she’ll have down days, and there’s a lot of times she’ll be in the hospital.

The children, whose ages ranged from primary to college age, are an important and integral part of Ie’s daily physical and spiritual support (Photo 5.87). They also helped their sister out by unpacking medical supply boxes and stacking them next to Ie’s haemodialysis machine. These tasks were part of their ordinary chores the children did at home.

135 Ata pointed out that my mother was a player of one of the first netball teams.
Ie: Well my sisters, ‘cause I have four sisters and one brother...they like um, get all my supplies (grinning). Like when they come, they like get it ready, like I taught them how to, like, what to put in the stuff in the bag and that and then they just get it ready for me. Um, my Mum, oh, they do a lot of travelling, my parents, like bringing me in to dialysis when I’m in hospital, doing that, um, just coming in like every day.

Emo refused to allow her husband to dialyse at home because of concerns about her grandchildren safety around the haemodialysis machine. It would require extra supervision but more importantly if there was an accident or an emergency, Emo lacked the confidence or knowledge about what to do.

Emo: It doesn’t end there, because there’s the two of us, plus two small children that live with us, my grandchildren. I don’t want any problems to happen – true, there is a separate room with everything in it, but children are curious, aren’t they? That’s another reason why – as you can see, neither of us haven’t had enough education or proper
When Ie took up full-time study, she said that her younger siblings had specific tasks at home that really made dialysis easier for her. This sometimes required the children to be supervised by the adults of the household.

*Photo 5.84 Children and dialysis*

**Ie:** Well, I always tell them it would be easier if they pack it, like pack it the day before and just bring it, and put it next to my machine... oh, when I was studying and that, that's what they did. I think it was just in the beginning, when I started first dialysing, yeah it was hard for them, 'cause they would always be bringing the wrong stuff up...

As the eldest, Ie used her authority to instruct and discipline her younger siblings especially when they were distracted from completing their chores which involved them carrying dialysis consumables upstairs to their sister’s bedroom. Often, Ie said that she had tried all means of persuasion to ensure that the children did their ‘dialysis chores’.

**R:** What’s that like for you to know, I mean to depend on them and sometimes they might be grouchy - which is normal for kids?

**Ie:** (Laughing) So really, the have to kinda thing...they have no choice! (Giggling)

**R:** Absolutely, so you have a good laugh?

**Ie:** Yeah...just because they’ll like, “Ahhh (sighing), oh, it’s heavy!” But then, they’ll do it, they end up doing it (laughs) um, really, they’ll just do it, like if I tell them to do it, and they moan about it, I’m like, “You’re gonna do it aye? You know you’re gonna do it aye! (Laughing)…and they’re like, “Ttt. Oh, okay!” And they’ll just go do it, and because I’ve got - there’s five of them.

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136 Samoan Translation: Emo: E le gata foi lea ia nao maua foi ma tamaiti lati toalua lea ua matou nonofo nei, lau fanau, oue musu i faaletonu se mea foi lele moi a ole potu faapitoa le'a tuu ai mea faapena ia ole tamaititi ia e ulavale a? Pei ole mea a na tate puipui taia ia ilona ola ia umiumi ma, ia ma leisi mea ia o - ia silaia foi ia o maua ia ia ele lava ni aoaoga malamalama lelei ai mea faapela tau o machine.
Despite the collective support that was available at home, the children’s mother had to supervise the children whenever they refused or avoided completing their household chores. Unmet expectations and the effort involved in supervising the children sometimes caused stress for Ie’s dialysis.

Ivi: ‘Cause, if I’m not here, the kids would be carrying the bottles up for her, and then, there’d be times when she’d have like, have disputes with her sisters and that, and then they’d say, “Oh, we’re not carrying the bottles up!” And she used to get really angry.

When Uga talked about the photo she produced of her son’s shoes (Photo 5.90), it was to convey the depth of “distress” she felt as a mother whose son had been diagnosed with CKD and undergoing dialysis to stay alive. She was also undergoing match-up tests so that she could donate her kidney to her son. Within 12 months of our last interview, Uga had successfully donated her kidney and Uso stopped dialysis.

| Photo 5.85 Samoan baby’s feet, Samoan man’s feet |

Uga: ....And that one of the um, shoes and the jandals, the jandals are Uso’s shoe size now, which is quite large, being that he’s quite tall, and got, Samoan feet (giggles)....Big feet yep, and what I was trying to do with that photo, I was, (sighs), I mean it’s quite staged, ‘cause these, the little shoes that are in there are actually his first pair of shoes. ‘Cause I kept his first pair of shoes and Ufi’s as well.... It’s like, when you’ve got a little kid, you don’t, and I know that terrible things happen to people’s children all the time logically, but you never really think that that’s what’s gonna happen to your child. So, although Uso’s you know 23 years old and 6 foot four, for me, he’s still my child, yeah, so, so that’s why I took that.
Uga’s photo of the baby shoes (Photo 5.91) raised real interest amongst the other family members. Her husband admired the creativity involved and admitted that compared to his wife he found it difficult to express his feelings about his son’s illness.

Usu: *Why did Mum just take a photo of some shoes?* (Laughing), not seeing the significance in them I said, “Do you know whose shoes they are?” He says, “Are they my old, my shoes are they?” I said, “Yeah, those are your shoes from when you were a little kid as well”; and then it hit him!...Yeah, you know, but Uga’s always been a deeper thinker than me (laughs). I’m always just off the top of my head, and then later, and then I will keep to myself what I really feel.

Osi’s picture of the blue bucket at the front entrance steps is where family members congregated and shared progress reports about their mother’s palliative care.

![Photo 5.86 Smoko-bucket, time to debrief](image)

Osi: *This one is like the bucket, where we put our smoke butts in... we spent a lot of time, cause like that was our converse area...my Dad, my brothers, sister-in-law, you know. After, ‘cause I’m, so, I’m such a drama queen...I have to go for a break...go outside, smoke, and if there’s someone out there, I’ll stay out there longer than I should... because I found it really, really difficult to see a woman who was so strong who would get in the car and just drive off and do whatever she wanted to do, get up in the morning and just walk. I mean, she had to be a strong woman, to be, to put up with us...yeah that was really hard for me, not so much the physical, but the emotions that went with it...*

5.5.2.2 Seeing and valuing the same things

Ufi and Uga produced two similar photographs (Photos 5.92 and 5.93) and provided similar reasons about why they had chosen the same wall and photographs. For Ufi it was an expression of sadness for her brother and the inability to play competitive sport like he used to. Instead, her brother’s days were filled with dialysis.
For Uga, it was an opportunity to talk again about the missed signs and symptoms that were her associated with her son’s declining kidney function. She had begun piecing together past events when her son became sick and the sense of regret of not having identified the need to take him to the doctor when they should have.
things like when he was year 13 at college. When he was repping, and also playing for college...he wouldn’t go running, on training runs, and we’d watch him, and he would go and put on, he played goalie...which is of course all quite bulky, and then, he wouldn’t be able to run, and that obviously suited him...just with that benefit of hindsight, he was just starting to lose energy, from probably that time on.

The red heart contained in both photos is a hanging wall tile, an important symbol of love that she had when she framed the photos of her children on the wall.

Photo 5.89 Ufi’s treasured family photos

Uga: Oh, the heart tile, yeah, I guess that just happens to be on the wall there, but, I kind of liked it, I guess because its round family, um, photos of family, and though you can’t see them very clearly, um, Ufi, who’s now 18, Uso’s younger sister is in here, along with my god daughter who’s a year younger as well, and my god daughter’s mother ( ), is Uso and Ufi’s god mother (laughs.). There’s a photo on this wall as well of Uso’s cat, which is long gone but it’s one of those child-hood things.

Ufi took a photograph of the framed family photos kept on the wooden shelf cabinet in the family lounge (Photo 5.94), to represent the sense of pride that she felt for her family. She also wondered whether others in the study would make similar photos of their framed family photographs; and of course many participants did.

5.5.2.3 Agreeing to modify traditional gendered arrangements for home dialysis

The formal roles of caring for the sick, elderly and young is normally the domain of women and young people, and less often carried out by adult male family members. In Samoa, family dwellings within the village setting are socially and more distinctly arranged by gender and hierarchy. In Samoan culture, the connection between spouses and their respective families is symbolised at the Middle of House by the...
feminine *toga* or fine mat called the *le Nofova’a*. This mat is a gift given normally by a woman’s family to her newly betrothed partner and symbolises the long and arduous journey that is ahead. When Olo made the decision to share the primary duties of care not only with his daughter but also with his son, it fell outside the norm of Samoan-gendered arrangements within their extended family.

*R:* Olo, what would happen you if were in Samoa. Do you think if it would be different?

*Olo:* Oi? Yes there is a difference; I know there is a very big difference because there are a lot of family members living together? It’s good, good for the family too, but as I explained before, it’s only myself and Ofe living here at our house with the ma’i (patient), and it’s easier…

When Olo was approached with offers of assistance by female relatives they were concerned that his duties as a primary carer had extended outside of his normal responsibilities as the patriarch of the family.

*Olo:* Well it’s true, when it’s about patients and illnesses, set aside the matai and focus on the duty of alofa towards the patient; just like what we did with my wife. So no, it’s not important my matai title – caring for my wife was important to me. That’s why the women of my family came – but they have their own responsibilities to their own families, their children and their jobs… they really cared about us.138

The extended family were also concerned about his son’s involvement.

*Ofe:* Oh, on fa’aSamoa… probably that, Dad really shouldn’t be bathing Mum…’cause it’s um, oh, I don’t know what they call it, um yeah, yeah, it’s probably not right. Or even for a son, ah, which, yeah I’ll probably agree with that, oh, well, for a son you know, not to um, see Mum naked, you know sorta thing, and things like that. But I suppose if you’re in a situation where you’ve got no choice…

Despite the fact that both his wife and daughter showed reluctance and discomfort about his involvement, both he and his son seemed to share a pragmatic and practical perspective about the issues of care.

*Olo:* And in my own experience, it’s much better to be at home, it’s easier and I believe it’s a great help to the hospital, because it’s not just one

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138 Samoan Translation: Olo ia e moi a, a oo I mea faapea mo ma’i ma gasegase ia ta’atia a I le matai ia ae fai le galuvege alofa ile ma’i latou. Pei la olo matou faafegai ma si ou aiga. Ia leai ia e le sili ae au ou igoa matai I lou alofa ile mea e tatau ona fai ilou aiga. Atonu mea fai nei e emai ai teine le matou aiga ia fai latou aiga, ma fai mai e ia, ae leai ua ou fai atu a au ia “E leai, o e faigaluega na foi e ati e tou aiga au sou a pea olea e faigofie”. A aua e iai leisi Tamaitai na na sau leisi aso matamata ile faiga uma e mea, aua na fai mai sei ou alu atu ia na sau a lea e sili ia la sou sau, na ua e vaai iai e faigofie a, ia fai mai laia, tui laia sei ou sau cuta, “Oi alu e pito toatele a lau fanau na e aoaoga, alu alu e faigaluega, ae tuu ai pea tae”. Ele, ia well a a clo latou alolofa mai foi lele ma le tulaga e iai ia ae leai tate. Taiio iai i nisi ai lou atonu.
person that’s got this disease, there are a lot of people starting to get this disease.\textsuperscript{139}

Olo also had to consider the complex issues related to his wife’s CKD and dialysis treatment. Handing over responsibility was not easy to do with people who have little understanding about dialysis and CKD.

\begin{quote}
\textit{Olo:} ...but then have to be careful because other family members don’t understand [about dialysis], a?\textsuperscript{140}
\end{quote}

Because of the normal gender divisions, Osi said that privately she struggled to accept her father’s increasing participation in her mother’s personal care but her concerns soon grew into admiration.\textsuperscript{141}

\begin{quote}
\textit{Osi:} You go to church, and, lei lauga (Dad’s preaching a sermon as a lay preacher...then, come home, and just roll up his sleeves, and for me, I, I just couldn’t be; yeah, it wasn’t till towards when my mother was getting really, really sick was I able to be in the same room as my Dad... just the fact that he was cleaning her mess; that was really, really, yeah, nah. It was, and I thought, “Gosh Dad, you’re just really awesome”. ‘Cause I couldn’t think of anyone else that would do that.
\end{quote}

Her mother also had deep concerns that her husband, was volunteering to do mundane and menial tasks outside of his station as the patriarch of the family.

\begin{quote}
\textit{Osi:} So, I, and my Mum felt really uncomfortable ‘cause she also felt that, you know that him being a matai (chief) shouldn’t have been doing what he was doing.
\end{quote}

\begin{quote}
\textit{R:} So she was respectful too of him and his position and role in the family...now and then she would say, “Talofae ia Olo (poor Olo). That’s all she said. I go, “No, Mum because, he loves you, anyone else would’ve left, he loves you Mum you know?”
\end{quote}

Being responsible for his wife’s health at home Olo was fulfilling his duty as a ‘navigator’ by safely steering the canoe specifically during this very difficult stage of palliative care. In some ways there was renewed depth of affection as he found ways to allay her fears and making her comfortable.

\textsuperscript{139} Samoan Translation: Olo Tiga na maligi loimata ole matou aiga ae pei ua faifai ua masani ia ua ia ua fiafia foi iele lae e fai a e au. E manava mai si ou afafine ile sau ia isi aso fai taelega ole Tamaitai. Ma o lau na vaai iai le mea e sili atu le fai ile fale e faigofie ma ia oute talitonu foi o leisi lea fesoasoani sili foi lea ile ofisa latou ole falemalei, aua ele toatasi se tagata maua ia mai e toatele tele tagata ua maua utuava l tei le mea lea.

\textsuperscript{140} Samoan Translation: R Ana faapea na tausi ai le olomatua I Samoa? Poo lea se ese’esga? Olo Oi? Iona e iai le esesega, oute lagona it’s a big difference aua o Samoa ia foi lele ia e toatele tele aiga e nonco fa’atas i a? E lelei ia, lelei ia the aiga foi ia, pei lea oute fa'amata nao au ma Ofe lo matou fale ma le mai, ia faigofie ai. A, ae a ave, ia la ua fai mai Samoa mea ia ae oute taito iai oute leiloa poo lea aua tate lei vaai iai l mea poo lea le tulaga ci iai, oute leiloa poo fai ai nai machine faamama foi lele. La iai ae elo faia dialysis e lei oo iai la dialysis aua tate lei loa ita ia mo... oute loa e fai uma mai a ii ile falemalei, ia sao la leaga e tatau ona faaetete foi lele aua e leo ia se malamalama foi ia o tagata o aiga a?

\textsuperscript{141} Olo had also led an active political life as a former Member of Parliament of the Samoan Government.
Olo:  No matter how many times my wife’s eyes filled with tears, but (I) carried on with it – she got used to it, but was happy I was the one doing it. My daughter would finish work and come home and find me bathing the young woman!

As duties of care intensified, Ose and her brother were worried about the workload that their elderly father had taken up as a primary carer.

Osi: ‘Cause of, you know my Dad’s such a proud man…like Ofè would get up in the morning before he goes to work to do my mother’s dialysis, then Ofè would wake up my Dad and then it was all on for my Dad: the dialysis, then the breakfast, and then the bathing her, and then just putting her on the wheel chair, and then doing her tea you know, and um, he’d be knocked out by the time we got home.

Initially, Osi tried to exclude her father from duties around their mother’s daily ablutions and personal care. As she talked affectionately about him, she acknowledged that he provided vital support at home when she and her brother were unavailable.

Osi: When my Mum had come out of the hospital and we tried to get a routine for her to wait for me when I’d come home from work. And I remember when I got to (family home), and I saw all the towels and the ie afu (sheets), and I walked in…and I asked my um Dad, “What, had happened”. He said that he knew my Mum had messed herself but didn’t want to say anything, and he kept saying, “You know have you messed yourself!” And she said, “No, I’ll wait till Osi comes”. He said, “But, Osi’s not going to be home by half past five,” and then, he said, “No you can’t sit!” And so, he just threw himself into it. He didn’t, you know he didn’t get any training, or shown how to do it, he just did it.

R: The best way he knew.
Osi: The best way he knew…

Whilst, having heard that some extended family members were unhappy about her father and brother’s involvement in their mother’s care, Osi was determined not to be distressed by it.

Osi: So, yeah, that was, yeah, that was um, and I know family, especially my Dad’s family, the extended family, I knew they’d, they would mumble, saying you know, “Ele tatau na fai le Toeaina (This isn’t something the old man should be doing)”. ‘Cause I know my Dad’s family really well, but I thought to myself, yeah, you guys talk, but you don’t do anything to help… So we did our thing, and then people realised, we, did our own thing, the (nuclear family) just did their own thing, yeah, um.

She knew that the extended family had strong expectations that as the only daughter she would take up the mantle to care of her mother full-time to relieve her father’s
involvement. Osi laughed as she retold a private joke that she and her father shared during bathing times about her mother’s love of perfumes (Photo 5.96).

![Photo 5.90 Mum’s favourite perfume and sculptured gift from Osi’s husband](image)

Osi: They would say, “Oh, that’s not my job, you know, she’s got daughters, or sisters or female cousins”. So, to watch you know, like knowing that he’s cleaning her mess, cleaning the private, you know, and um just making sure everything, yeah, and he was another one that (got) carried away doing the perfume as well!...When we buried our mother we had a little bag...’cause she loved clutch purse, and put in a Red Door in there for her...

For Olo the experience he had as a primary carer reinforced his view that home dialysis is an appropriate and effective option for Samoan families. Families should exercise their rights and responsibility to care for their loved ones in an environment where carer agencies are available for home care.

Olo: It’s easier to do it within the home, there’s no difficulty. It’s my opinion, there’s a place within the home for it to be done properly. And, even though there are paid caregivers who come every day, I tell them, “No, leave it”. Even the bathing and that, I’m telling you, I was the one that did everything! I had no trust in any of the Palagi women (agency caregivers) that came to do the bathing, so I did it all and everything else.
5.5.3 Samoan culture and identity

5.5.3.1 The important role of Tatau/tatoo in Samoan masculinity

Another elderly participant in the study had talked about his role as an Orator in the community too. During our interview Efu pointed modestly to his abdomen and said that he was careful to conceal the surgical scar near his peritoneum whenever he had to appear in public shirtless and dressed in traditional Samoan attire. Although, he felt a little self-conscious about his scar it did not prevent him from carrying out his cultural duties.

_Efu:_ At the time I got sick and have remained sick…what happens the fue (orator's whisk) and the to’oto’o (orator's staff) is passed to me. I usually orate at events for the village and the church. In relation to the matai, when doing oratory, no shirt is worn, a? Just the ie (waist wrap-around)...so I wear the ie so that it hides the thing that was done here (pointing to his abdomen). So I carry on with my matai duties, but I’m also an Alii (chief).^{142}

Efu attributes his capacity to absorb a lot of physical pain and psychological discomfort associated with CKD on the basis of having lived through the intensely painful tattooing procedures as a soga’imiti (tattooed male) during his early 20s. As an important Samoan tradition (shown in Chapter 3), traditional tattooing is an initiation ceremony involving can take up to several days, weeks and months. Ata said that he had a very fast recovery after being tattooed and this experience has always served as a significant motivational anchor to him and the way he manages himself as a dialysis patient.

_Efu:_ In Samoa it’s said amongst us Samoans, lots of people say, a person who gets a tattoo is unable to climb up the niu, a? Me, when my tattoo was finished, nearly two months later, when my tattoo was done, I climbed the niu (coconut tree)!...That’s why as I said, “I don’t believe the talk that a niu can’t be climbed!”^{143}

As will be shown later, despite his feelings of great anger and frustration with CKD, Efu talked enthusiastically about the importance of the Samoan language (gagana Samoa) and land (agaifanua). He then narrated two key stories about the Samoan

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^{142} Samoan Translation: Efu í le taimi a na ou ma'i mai a, o’o mai le taimi nei, ma’i mai a...pau a le mea e tu’u mai le fue ia ma le to’oto’o, go o a’u la e masani na o’u lauga I mea fai a le nu’u ma le aulotu...Ole mea ole matai, a lauga e e leai se ofu tino a? Na’o le ie, ia tuu laia pe fafe fa’ea fa’eaonaga aga...la e mafai ona tua tutoa I lalo le mea lea ia, sa mafai a na fai a? Ou tago foi la sulu lou ie ua nana ai la le mea lea sa fai ii (pointing to the part of the body) ae fai a ona o au la olou matai, o au ole mea ole ali.

^{143} Samoan Translation: Efu: A’o mea sa ia Samoa, na matou e Samoa fo’i mai ole tele o tagata, tagata a latou tatau, ta latou pe’a, le foe mafai los fe’e’ei I niu, a? O a’u na uma loa ta fo’u pe’a, pe lua masina, na ta ai fa’u pe’a, a’u a’i ile niu...Ole mea la na, e fo’i gale, o’u fai atu, a, oute le talitou la le toutala lena fai mai e le mafai na tou fe’e’ei.
culture, the first story in reference to the Samoan ocean tide called *Tai Samasama* (Tide Golden/Yellow)\(^{144}\) that commemorates the socio-politico-historical origins passed on by the Tuimanu’a to the Malietoa. It provides the origins of Samoan feminine (*toga*) and masculine (*oloa*) cultural wealth in the exchanges for hospitality and prestige in Samoan society. (Refer Appendix 11A Golden Ocean Tide – Taisamasama)

The second story is about a water pool *Vai ole Tuimanu’a* (Pool of the Tuimanu’a) and the healing powers of the King of Manu’a to resurrect a man with a sacred chant who died after swimming the forbidden waters (refer to Appendix 11B).

As I reflected on Efú’s Samoan narratives he had offered these for the study so that families might be comforted and uplifted in times of hardship particularly within the public health system. The rich symbolism of the ‘healing waters’ reflect the ocean and springs of Samoan Geomentality could also be a way of revitalising culture in the contemporary lives of Samoans living with CKD.

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5.5.3.2 **Mixed Samoan heritage**

Ufi was proud and confident about her Chinese and Samoan heritage, hoping one day to learn her Samoan language.

*Ufi:*  
Well everyone thinks you’re Māori, some people think Brazilian, but (laughs). Yep, especially when there’s the same amount, Chinese and Samoa. ‘Cause yeah, you can’t really see the Chinese, our eyes are a

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\(^{144}\) Taisamasama is a coastal area of the Ta’u (Manu’a-a-tele) Island in the Manu’a Group.
little bit chingy...I just wish Dad had spoken it us when we were little, so we grew up with English and Samoan, so we can speak it now, but, it's alright.

Ufi’s father Usu was also proud of his Samoan/Chinese heritage but like some Samoan families was discouraged from speaking Samoan in preference of English.

Usu:  ...I was born here in New Zealand, and actually been discouraged from speaking... ‘Cause I’m, I’m, I’m quite proud to say I’m a Samoan, you know... A real Samoan to me, you know, they, they actually can speak the language....

When Usu turned 30 years old he was conferred with a matai (Tamali‘i‘i) title from his mother’s family.

Usu:  Mum wanted me to know about these Samoan things (smiling)... I couldn't have Grand Dad's name, so, I had this name ( ). And my mother took on the ( ) title because, yeah, even though I'm not the oldest son, my mother wanted me to have that title in our line of the family! (Laughs)

When his brother rang him for advice about taking over the chiefly title previously held by his mother, Usu advised him to take up it up as long as he was willing to travel frequently to Samoa and be available for the family while living in Auckland.

Usu:  And I said, “Well unless you’re prepared to go over there, and actually be involved in it, then, say no. Because, its, it’s irrelevant to how, if it’s gonna be, make a, make a big change for you, and you’re going to go ahead and do it. Then, yeah sure, you know, but you have to find out exactly what all the expectations of you are and if you’re able to meet them.”

Usu’s Samoan/Chinese background, combined with his Christian values formed his perspective about the central importance of family. Below, Uga’s photo of Usu after a successful fishing trip (Photo 5.84) and Uso’s photo of himself with his two sisters at a look-out point overlooking Wellington’s west-coast (Photo 5.85).
Usu: I slowly come to the conclusion that, it doesn’t really matter what culture you say you are, the only real values are the ones that keep a family together… just caring for one another, and loving each other…The ideals of every culture, I think are all pretty much the same, I think everyone wants to live you know a happy family life, and they want to be able to share and care for each other and have um, loving relationships in their family unit, and their extended family…If the ideals are all the same, then I don’t think, you know, if the ideals are the same, then to me, that’s a good culture, no matter what colour your skin is.

5.5.3.3 Samoan traditional healers

Emo switched conversation to talk about her own health. Some years previously she had been diagnosed with a chronic liver condition having contracted Hepatitis B. She underwent medical tests with her general practitioner and was given a range of medication. Later Emo sought treatment from a Samoan taulasea in Samoa (traditional healer) where she was given an herbal remedy to drink each day. Interestingly, the taulasea’s remedy involved herbs diluted in a glass of water with which Emo’s ata (reflection) was believed to be submerged. With the help of the herbal infusion, the healer believed that the healthy cells and organs in the body were being protected from those which were unhealthy; thus, restoring health and wellbeing.

Emo: What the Taulasea did was a healing for clairvoyance, insight/awareness (malamalama). It was done in a glass that was filled with water right to the brim of the glass. The old man then handled a cloth soaked inside of the water and wrung it into the glass. He sat facing it and then he catches (pu’e) your picture/image (ata) inside of the water glass, ah? It was green, the liquid that was wrung; even the white things that circulates is brought inside - is caught/captured (pu’e) by the old man, all the disease – don’t understand how.\(^{145}\)

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\(^{145}\) Samoan Translation: Emo: Ole faiga ole vai ole toeaina, ole malamalama, fai atu le ipu
The Taulasea’s treatment helped Emo to alleviate some of the physical pain she had been experiencing in her arm, which she said was symptomatic of her sickness. Interestingly, the treatment process echoes the Ofe Pu‘eata story told in the earlier epistemological Chapter 3 about the importance of water pools and the use of water containers as a site or conduit for supernatural phenomena (see also Appendix 3.4).

Emo: I don’t know about it, my arm hasn’t been numb, no pain; the toeaina’s (elderly man) funny, said to just drink the vai (herbal remedy) anyway. If there’s anything that takes me to Samoa, I’ll also go and see him.145

5.5.3.4 Barriers to kidney transplantation or Tautua toto

In Chapter 3.2, “Five Complex Forms of Traditional Social Duties”, the column titled Tautua Toto or Service of Blood owes its origins to the dedication of warriors and soldiers specialised for the protection and safeguard of Samoan society. This traditional role is the closest that I could find to justify the appropriate use and sanctioning of organ transplantation in our contemporary society. In this section I present the issues about kidney transplantation that participants were forced to deal with as an alternative for renal replacement therapy or dialysis. An interesting observation was that the elderly patients refused to consider kidney transplantation because of their age, co morbid diseases and the high risks to family donors. Those that underwent match-up tests for transplantation were the younger participants in the study.

Ata, Efu and Osi had all discussed the option of transplant with their respective physicians and largely without the involvement of their adult children or extended family members. Ata’s sons agreed to find donors amongst their family and after two compatible matches were confirmed the physician was unable to convince Ata of the merits of transplantation.

Ata: Dr. ( ) rang me so I went to his office. He said he had the results from my two sons are and that they were matches for me and that any time I wanted to do my transplant then yes. … I’m sorry, and I was looking at the man, I think he was thinking how silly I was in making that decision, there are so many people who want a transplant, I said, “No thank

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145 Samean Translation: Emo: “Ia, a te leiloa e le ai, se elei pe lo’uta lima e leai se mea tiga, malie ia ole toeaina, fai mai inu pea le vai. E iai se mea otei latu ai i Samoa, otei toe latu foi e va’ai.”
you.” So, that’s how it’s been left. He kept trying to talk to me about it and that I could live well on the one kidney but I said no thanks.147

Despite the invasiveness of dialysis and the increasing fragility he experienced in his body, Ata believed that a kidney organ would be wasted on him given his other comorbidities of hypertension and cardiovascular diseases. He was also unwilling, like Efu to expose his children to a life of dependency on dialysis in the renal unit.

Photo 5.95 Ata’s photographs of his children’s wall of photos

Ata: But I said to him, I’m sorry, I don’t want to a transplant, I love my children very much, aye? I didn’t know if I was going last until next year and I didn’t want any one of my children to suffer because of me.

Photo 5.86, following from his earlier photographs of framed photographs, is Ata’s photo of his children. While he said that he had many potential donors (Ata had more than 20 grandchildren), he felt unable to consider transplantation as an option for himself because of his negative experiences in the renal ward as a patient and the potential dangers associated with transplantations generally.

Efu and Olo purposely avoided having discussions about organ transplantations except with their spouses. Both of them refused to involve their children or consider them as organ donors. Olo’s wife was offered a kidney from the deceased donor registry, but refused it because of the potential complications of post-surgery, thus far outweighing the benefits of a transplant. Neither of them informed their children that a kidney had become available and that transplantation was refused. Osi said that her parents were convinced that transplantation was not a viable option because so

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147 Samoan Translation: Ata: “Tei la ua telefoni mai ole ali o ( ) ou alu atu loa. Tei a ua fai mai leinoa, ia lea ua maua mai le test o lau fanau e toalua tou te fetaui, ia any time ete mana’o ai e fai sau transplant ia. Ivi ae ou fai atu tafi, I’m sorry oute le mana’o e fai sau transplant, oute alofa I lau fanau a? o au lea e leiloa pe oute aulia next year ae oute le mana’o la e suffer seisi o la’u fanau talu ai ona o a’u. I’m sorry, ia ua tititilo mai le tamaloa, ai ua faapea le tamaloa, matu’ai vai lea tele lele. O la e toafia tagata lae e mananao e faata latou transplant, fai atu no thank you. O la la u tu’u ai fa’spea. Ola fia e fai mai ia au, fai mai e cla lelei a le tagata ile kidney e tasi, ae ou fai atu lela faafetai.”
many of the transplant patients they observed in the ward had very difficult recoveries.

Osi: Yeah, they had the kidney transplant, but they had problems, so they were checked into the hospital, so my mother would see that, and she’d go talofae, you know, they’d go through all of that, and its, not working, so yeah, it was just, you know, I don’t know what her and, you know, probably decided

Efū and his wife refused transplantation in light of the fact that they had already lived out most of their life and did not want to put their children in potential danger. Instead, they discussed funeral plans to have Efū’s body cremated and his ashes returned back to Samoa. Despite cremation being a devout Catholic, Efū believed that it was the most practical and the most affordable option for his children.

Efū: For me, when the time comes for me to die on New Zealand soil, I want when I die, for my body to be cremated, a?...If I’m cremated, taken properly and put somewhere, moved around and taken. So when it comes to the time, when my son has enough money, then it’s easier to bury ashes, a? And take me to Samoa... or whenever he gets there, leave me in Samoa before I’m interred... the costs of coffins freight on the plane, there’s no air fare, just a simple box...buried next to my mother on our land...if they (my children) leave me behind wherever they are on this earth they go to, at least I’ll be resting on my land?148

Ie was waiting for a deceased donor match for nearly eight years when I met her. She and her mother had just begun the first stages of matchup tests for compatibility.

Ie: Me? I wanna transplant, the future really, transplant, and then I just wanna go out and try to see the world really... Oh, not to do, being on dialysis, yeah. I just wanna transplant. That’s why I reckon...why it is hard for PI patients to get a transplant. Not only PI patients, but all patients really. There’s no advertising out there, about transplants and that, and if you’re in Wellington and you’ve already got a transplant waiting, you’re waiting, you’re waiting for how many years just to get it, kinda thing.

But for Ie’s mother, becoming a donor required a major change in lifestyle and a new regime of getting fitter and eating healthier. Ivi had already lost her own mother to

148 Samoan Translation: Efū: O a’u, a o’o mai le taimi outi oti ai, eleele o Niu Sila a ia. Mana’o a, a’u oti, ia susunu lo’u tino, a?... Ae a susunu a’u, ave fa’alelei, ia, tu’u se mea fo’i le gale, ga feo’ai lea ma feave’ai. A o’o loa le taimi (pause) ua uma ona ou tai lo’ai鲑tai’iti a (pause) e aoga, o’o loa le taimi lena ua e iloa ua maua ni au tupe (pause) aua, na ea faigofie a lae teu lefulefu, a? Na’e alu loa lea ave a’u I Samoa. Pe te latu fo’i Samoa oea le umi, e ta’atia a’u I Samoa, fa’ato’a tanu, ia e leai a se vevesi tele, a? Fo’i ni mau, fa’apea tau fotogi se pusa e ave ai ile va’alelei, pe tau fotogi se pase leai na’o se atigipusa po’o lae, ia na avatu loa, ia tanu a’u I tafatafa, ona ga o lo’u tina a lae lai nei ile matou fanua, a? Lae tanu mai nei ile matou fanua. A ua t’ai a a la a’u ga po’o fea o’inei itu ole fa’aloli’ita fofou fo’i ai, a la ua ou taoto tonu a a’u I lo’ai, I lo’ai aiga moni ma lo’ai fanua, a? Tusa a la pe tou te le toe manatu atu aia la a’u, ia a la ua ou taoto atu, I lo le o lea, ae ti’ai a’u se mea inei Niu Sila (laughs) ia ae, pe e sili ai lena, e faigofie fo’i.
chronic kidney disease and so hopes of being able to donate her kidney to her daughter was important.

Ivi: I'll say, oh, and here and I went and did our cross matches, we've gotta wait for 6 weeks, they had to take it, send it to Auckland...because I'm preparing myself, and I'm gonna join this programme, Sure-Slim programme and the gym...but I really need support from them...but I rung the um, transplant lady ( ) and she was lovely...and then, we got our letters to go and have our tests together one morning, and reading that, I was excited too...cause I feel that, it may just be me...probably be the one...to be able to help my daughter, you know after all these years...cause, my Mum had diabetes through the eating habits and that, my dad's a healthy man...but I'm really hoping then, um to be a donor.

The prospect of a transplant allowed Ie to think more concretely about her future hopes and dreams of having a partner and a family.

Ie: Someone with no job, no life, (grinning), um, it's like, that's of the world - I don't want someone like that. That has no culture in them, um, yeah...Well I've got brothers and sisters, so they are children for me, far! just looking after them ...because I reckon 30 is the age that I'll probably be settled, like with a good career, yeah, and that's why I look at 30 as a age to look at kids.

In this chapter, I first discuss how children and spouses within families are important in providing assistance for home dialysis patients.
Section D - The major challenges of home dialysis

Table 5-9: Key Themes: Section D - The major challenges of home dialysis

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As highlighted earlier in the epistemological chapters the traditional domain of care for unwell family members involves the mundane and messy day-to-day tasks, particularly within the indoor environment. While many of the experiences are about participants lives at the ‘back of house’, this section pays more attention to the public and corrections authorities who hold the most responsibility for the services that families receive. Figure 5.4 (below) are the main obligations that families discuss that are mostly mediated by formal services that are negotiated at the ‘front of house’.
The renal sector would define the roles and responsibilities carried by families as ‘non-clinical’ in nature. Through their stories families revealed how they often have to absorb the financial and psychological costs as carers.

5.6 Compliance and conditions
5.6.1 Nutrition and diet

In addition to the adherence of the dialysis routine, patients have had to observe the strict dietary and quantities of certain foods that generate different levels of toxicity in the body. In le’s view, very few people understand or appreciate the serious nature of compliance around dietary and nutritional intake.

le: ‘Cause, just the whole like um, they [nurses] don’t like it…a lot of patients take that, say that, so it’s just funny…

R: Why do you joke about it like that?

le: Just because um, we know that we shouldn’t think of it like that…well, to me I don’t see a problem with it, ‘cause it’s, it’s boring if you like, no, I can’t drink this, like if you’re like really strict on yourself, reckon it’s real boring, ‘cause then you’re probably only allowed to have water and nuts (laughs)…
Ie’s advanced knowledge about the kinds of mineral and nutrients that can cause physiological and urological complications made her an expert about her chronic condition.

R: ...Do you notice it though when you do? ...why do are you not allowed to have it?
Ie: ‘Cause it’s bad for our kidneys or something… honestly (laughing), I don’t even know why we’re not allowed to have it…know that for phosphate stuff… It’s to do with the bones…Like it can get all brittle and stuff, and then we also have medication for it as well…oh, the reason why…you know, how potassium can kill you, so because our kidneys isn’t working to take out that junk of the potassium, dialysis is helping it… yeah, I know that, potassium’s like banana, cheese, chocolate.

She had her own favourite foods and her family knew where her favourite shops were (Photo 5.96). Her mother also knew how to help her adjust to the weekly dialysis routine by ensuring she had some of her favourite foods to take with her to the hospital.

Ivi: And we always go, this is le’s favourite bakery, every morning, every time she, I drop her off down at the ( ) shops; every time I drop her off at the shuttle. This is where we always go Monday, Wednesday, and Friday mornings.

Photo 5.96 Ie’s favourite food stop on dialysis days

Working around the dietary restrictions was part of the dialysis routine; eating junk food during dialysis is common, despite staff discouraging patients from doing so.

Ie: Like we always say, “If you wanna like, if you crave for something a lot and you need it, like chocolate or something, and you know you’re not supposed to eat,” I always say, “It’s best to eat it on the machine!” (Grinning).
R: (laughing)…and the nurses don’t agree with you?
Ie: Some do, but some are like, “Nah!”
Diet was a major factor in Osi’s household because of her mother’s diabetes and the photograph of the kitchen sink with its buckled drawers was as a permanent reminder for this (Photo 5.97).

![Photo 5.97 Sink that often overflowed with water](image)

Osi: When we’d come home from work, um, we’d go, “Ttt! Ua koe sūsū? It’s wet again?” And would go, “Oh, yeah Mum was at it!” So that’s why it’s looking a bit hunkery, ‘cause it’s kinda expanded, yeah, ttt and ah, so that’s why I took that and thought. Yeah, she’ll always turned on the tap and forget to turn it off and walk away...’cause she’s had like blackouts. Like when she’d drive in the car she’d have a black out because of her sugar and we’d come home, and like I remember being at school and she’d be like asleep on the bed; and I knew that it wasn’t right because she was supposed to be awake at that time doing whatever she normally does, and you know we’d touch her and she’s wet, yeah.

Uso felt that patients who dialysed at home should be able to have fuller nutritional consultations because they were no longer at the hospital. Being separated from the day-to-day renal services and the expertise of medical staff was an obvious disadvantage of home dialysis.

Uso: Nah, its ( ), but ah, yeah, it probably be good to just talk to a nurse, about maybe you know, even just your results. Might be your um, your target weight, what’s happening with that, blood pressure and all that kind of thing, ‘cause, ah, I don’t actually with my blood test results, they’re supposed to send them out to me, but they never do. But the hospital sees them, and ah, I don’t actually know what they are, but they, they ring them if they’re bad, but, I don’t even know what’s happening with them, (giggle). They just say, “They seem to be okay”, but yeah.

Patients at home should also expect more prompt return of blood results.

R: ‘Cause you’ve got to do those blood tests regularly don’t you?
Uso: Yeah I’ve got just the monthly blood tests for full blood count, and just all the levels in your blood, the potassium and all that.
When asked what advice he would give to patients who are starting home dialysis training Uso said that they should ask as many questions as possible about what nutritional intake and operating the haemodialysis machine.

*Uso:* Ah, keep your target weight down. Don’t drink too much (giggles). Um, yeah, I suppose pretty much, just ask questions, don’t be afraid questions, or, go back over anything you’re not quite understanding when you’re doing your training….Yeah, so, pretty much just um, make sure you’re fully confident, with, ah, doing what you’re doing. And um, try and learn as much as you can, about everything, pretty much, like diet, the machine, everything, and um, yeah, always, it’s always good to, I’d probably tell them too, just talk to other patients as well; it’s always, probably one of the better things for me in learning.

### 5.6.2 Giving up alcohol and leisure activities

Younger patients experienced major changes as a result of having chronic kidney disease. Photographs of beer and alcohol taken by Ufi were reminders of the time when her brother was “binging” after being initially diagnosed with CKD (Photos 5.98 and 5.99).

Ofe and Osi (brother and sister dyad) produced their photographs for the study, some 12 months after their mother passed away. When the family needed someone at home more regularly to take care of his mother, Ofe admitted that he felt compelled and obligated as the youngest sibling to be the one to do it. It was a time where he had to give up his sports and limit his contact with friends.

*Ofe:* Oh yeah being the youngest and also you know living here still with Mum and Dad… admittedly during the year I go sometimes I go, “Oh, wish I was doing this and that”…. I just kept thinking oh, and because, I was you know, still single that time, (my eldest brother is) married, Osi was married, you know I thought, and being the youngest I suppose, yeah, (pause) I thought, no, yeah I had no problems, or um, yeah, (pause), none, none whatsoever, no! (Laughing aloud)
So that one was meant to just be of the alcohol, ‘cause, um, when he first diagnosed and stuff, he kept drinking, um, well I thought that alcohol was the reason like why he got it in the first place, and I was quite angry at him for that.

During an extraordinary moment of the interview, Usu admitted that as a father, he struggled daily with the reality of his son’s condition and dealt with it by “having his head in the sand”. This was the reason he made so few photographs for the study.

But then, and then, then the last one (photograph) is of course, that’s the reality shot...and I come to the conclusion that, don’t really want to think about it, what’s going on (quiet, and pensive tone)...So, for me, the less I have to actually do makes me feel better.

He was extremely worried that his son’s “lifespan” could be “shortened” because of kidney failure.

I have to accept that that’s (dialysis) normal for him. Then, somewhere inside here, its, yeah, “Things are gonna be alright,” somewhere in
here. But always in the background is the worst case scenario actually, but I haven't worked through that yet, because, its funny...its just that sort of 99 percent sure that everything is gonna go good, but except there's one percent of doubt there, which...(pause, thoughtful).

When his son was made the “sober driver” for his flat mates to face the serious issue of social drinking and this relieved some of the anxieties amongst family members.

Uso:  ... but I've only done that (binging) maybe five times since I've started (dialysis) and it’s just really not worth it! (laughs)... But I've noticed um, my flat mates now, um, they don't actually go out, they've actually started to drink less. I'm not sure if it's to do with me drinking less...but I suppose it could be me, 'cause I always tell them now, “I just feel a lot better.”

These changes in social behaviour were commensurate with his son's management of CKD.

Usu:  He's gone from the typical... being in the flat of guys, where they're you know, party, party, go hard everyday, you know always broke two days before the next pay. Riding their motorbikes all the time before he really got in that, “I can't do that anymore!”

Home dialysis offered the opportunity of carrying out practical measures of support which would have been difficult if Uso had not agreed to come home.

Usu:  ‘Cause I mean we get to see him. We know that he’s been well looked after, been fed properly (laughs), because down at the flat they don't, we know that they don't always, yeah.

5.6.3 Relinquishing autonomy of the carer role to external agencies

Home care services which are contracted by the state to provide care to public health patients can be a major undertaking for a family providing renal palliative care at home. Recognising that their 72-year-old mother’s fragility was creating a heavier carer workload for their 75-year-old father (Olo), Osi and Ofe (sister and brother) began investigating the options of external caregiver services.

Ofe:  So (turning pages of photo album) on that particular day we had all those, the people from the services. I had one group, Osi had the other, basically we just went through the house, and just, saying you know, what would be quite good for us to have...and a list of things, what we needed, um, ttt... just to help us to look after Mum, yeah, to make it easy, and the first things we want...was like a hospital bed, um, services like the cleaning, um, you know.
Back injuries while lifting the patient from the bed to the wheelchair and from the wheelchair to the bath had been a major reason to seek external assistance.

Osi: Yeah, yeah, I think it was just the lifting from the wheelchair to the bed, to the commode, and things like that...It wasn't till towards the end because it not only damaged, like my Dad and I had sore backs, and we were forever going. I was going to acupuncture and so forth, um, ttt, and, also not knowing, if we were hurting her (mother), here.

About half a dozen agencies contacted the family offering to provide professional services; however they were confused about which agency would do what and how it might be co-ordinated. After a round of assessments and field visits to the house, they had very little communication and no follow-up about what needed to be done for their mother.

Osi: Yeah and so it was like different people that rang, and just ah, so we didn't have that one person who oversaw everything, so we had different people coming in, and that was more evident. When um, I just remembered three different [people] were you know knocking on the door that one day, and I didn't realise, that oh one was just to take ya blood, the other one was just to check the equipment. Oh the other one was to bathe her, and that there's a lot more people than I realise... so by that stage, everybody was allocated there...and there was this other agency that looked after the nursing, and then we had this other Samoan outfit that we hardly ever saw, um, and, then we had, you know just the doctor, her own doctor, who didn't come to see her until she had pneumonia. Yeah, there were so many paper work to be done, so we had all these brochures thrown at us, but Ofe seemed to be more onto it, 'cause he was there.

None of the external agencies that came to assess the family's case suggested any modifications to the bathroom for palliative care. The family did raise concerns about their mother's mobility but were told that they would have to cover the cost themselves to build an outside wheelchair ramp, a decision that they could make easily because they owned the house.
Photo 5.101 Anterior door and concerns of evacuation

Ofe: The entrance is very important, obviously reasons for ah, getting the wheel chair, closer to the time when Mum was um, getting weaker and weaker, um, and also, the, the lady used to come into bathe Mum, she always pointed it out, ah. I actually bought it up with the occupational therapist, but I think it got to the point where we might have to do it ourselves, we were actually just gonna build a ramp.

The issues with external agencies did little to ally their father's concerns about having 'strangers' in the house looking after his wife.

Osi: But they spoke to my Dad and Dad said, “No, I don't trust anyone”. I think the idea of strangers of coming into, into my Dad’s home, no, no, don't want that, you know.

Families needed to be given written information that can be reviewed easily so that the decisions around their loved one's care can be dealt with efficiently.

Osi: It would be nice just to get a package, or just at the hospital - this is what's going to happen; these, this is the agencies you need to know about and what they are offered….but yeah, but not knowing what we were fully entitled, and if we paid additional, you know, but just thinking, I know we're missing something out….

The family were also faced with the new problem of having to check that the contracted caregiver had been briefed properly about the job she was expected to do.

Osi: Oh, I think, oh (long pause) it would've been nice if we were told what they actually did, because we had one woman who came, and then she said, “I didn’t realise your mother was bed ridden. I was under the impression that she was able to look after herself, so we have to get someone else to look after your mother”. And that was just the sponge, sponge bath, so, it would've helped, it would have helped my Dad, if we had someone from Monday to Friday, to come in to give my mother the proper bath, shower.
Olo found it difficult to completely hand over the responsibility of care to the agency caregivers who came to the house and believed that ultimately the family are responsible.

*Olo:* It’s easier to do it within the home, there’s no difficulty. It’s my opinion, there’s a place within the home for it to be done properly. And, even though there are paid caregivers who come every day, I tell them, “No, leave it”. Even the bathing and that, I’m telling you, I was the one that did everything! I had no trust in any of the Palagi women that came to do the bathing, so I did it all and everything else.

### 5.7 Isolation at home

#### 5.7.1 Without spousal support

Ata knew that some of his colleagues in the unit were able to dialyse at home because of help from their spouses. He was a widower for nearly 20 years and the only person who he believes that could have helped him was his wife. Without any on-going support from a primary carer, home dialysis for Ata seemed again an unlikely option.

![Photo 5.102 No spouse to help me dialyse at home](image)

*Ata:* Olo’s\(^{149}\) wife and \(\_\) wife are both on bags and it’s all very well for them because they have their partners to assist them and stayed with them. In my case, it’s only boys in my family and my daughter doesn’t live with me, she just come and stays overnight…

Despite Ata’s outspokenness against home-based dialysis, he said that he would have preferred it to hospital dialysis, and that if his wife had been alive, it would have been a definite option for him.

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\(^{149}\) Olo and his family are also participants in the study: Family 3.
As Emo narrated the scenarios of her photos (in the third voice), she did so in a warm and jovial way, describing the family routine that parents and children have at home together at dinner time; although, sometimes Mother enjoyed some quiet time by herself after father and children have eaten.

Emo: So, like many other times, is standing in the kitchen cooking for the father of the family and the children (giggling)…. father comes home when he's finished his… and, then the mother has just sat down, is the last to eat, yes, all the photos are the same!… (Laughing).150

These are all part of the duties that the carer does at the ‘back of house’.

During the day, ordinary chores like washing occupies her time while ‘father’ is away at the hospital; she takes care of the home base.

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150 Samoan Translation: Emo: Fo’i mai ga le tamā ua uma laga, ia, ae faatu’aluatu ai loa le tinā mulinuli e ai (giggling), e a ata ole mea tasi! (laughing); R Manaia.”
Emo: And the washing machine that’s on for the old man, so that when he goes to the hospital they’re clean (washing). \[151\]

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151 Samoan Translation: Emo: “Ia o masani lava, ole tu ile umukuka, fai le kuka, aua le tamā ole aiga ma le fanau (ataata). Fa’amama ipu. Ole, ole potu pogisā lea ou te tu mai iai i nei (laughing). Ia, male masini ta-mea nae ina e fa’āti’eti’etī le masini ole toeaina, aua lae latu ile faelema’i lae e mama (taliie)”.

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5.7.2 Challenges of mobility and transport to hospital appointments

Osi made a photograph of the inside of her father’s car (Photo 5.108) to highlight the distress they experienced when they had to take their mother to her hospital appointments. Home visits should be an important aspect of palliative care, particularly for elderly patients.

Photo 5.108 Travelling to hospital appointments extremely difficult

Osi: I mean, we didn’t have the greatest of cars for a person who’s, bed ridden…Then I suggested…like down the track…”Well, how about they actually send out transport, you know to pick up my Mum to go out there for her normal check-up”. Can’t remember what happened, but, that didn’t come, nothing came out of it…but it would’ve helped, [for hospital] to actually [provide] transport… yeah like an ambulance or one of those mobile vans.

5.7.3 Services families need

5.7.3.1 Dialysis training for carers

Some of the concerns that Emo had about home dialysis may have stemmed from the lack of adequate information she was given by the hospital, particularly in relation to areas of carer responsibility. Nearly all the participants in the study talked openly about how the dialysis training provided at Margaret Stewart House could be improved and translated into Pacific patients’ first language.

Efu was keen to take home dialysis because he had been able to manage his dialysis again at the hospital and was confident about operating the machine.
Efū: …get there (renal unit) wash my hands… I like the machine that I’m on now, because with the machine, I get there and I do it, do all the injections, needles. The only thing I ask the nurse to do is to come and set the fluid levels that get taken out of my body and things like that.\textsuperscript{152}

Emo said that she was given pamphlets about the haemodialysis process when staff tried to encourage her husband to take up home dialysis again; however it did little to allay her fears about home dialysis and provided little incentive for her to want to find out more about haemodialysis.

\textit{R:} Did you understand the pamphlets?

\textit{Emo:} In the pamphlet, kinds of needles and talks about setting up the machine, but for me I wasn’t happy with it. It’s better to me, that he goes and does his dialysis at the hospital…’cause, if I get blamed, then the patient gets blamed too, whereas, it’s better for the hospital to be the ones responsible, because it falls on the nurses and that…\textsuperscript{153}

Uso’s felt that several improvements could be made in the haemodialysis training process for patients. One suggestion was that the “alone time” period which patients are required to do at the renal unit to gain confidence to dialyse on their own could be extended from two weeks to eight weeks. He said that patients need to problem-solve potential dilemmas that can arise during home haemodialysis and he realised this after he got a severe leg cramp and did not know what to do about it. The shock of not knowing what to do in that situation was an important lesson about his readiness to go home.

\textit{Uso:} You can still like forget stuff, I think it was le’s cousin… got some saline for me. Yeah, it was lucky, it would’ve been a minor disaster if I’d been by myself, yeah, but it’s probably good, like maybe just to go after hours, just a few times, when it’s actually just yourself there, yeah, ‘cause it’s definitely a lot different…

Uso wondered why so few elderly Pacific patients showed interest to dialyse at home and more importantly thought about whether the hospital’s services could be more readily available to patients’ homes.

\textit{Uso:} Yeah, I suppose um, especially with something, some of them too, just being older, would just want to be home a lot more, they probably really don’t wanna go out.

\textsuperscript{152} Samoan Translation: Efu: “Ia e te alu atu lava fa’amama ou lima ma fai au, o lo’u fiafia la ga la ile machine, lea iai i nei laga fc’i la le faiga o le machine, ia ote latu a’u ia fai le machine, fai uma tui a’u nila, pau le mea ou te fai ile teine foma’1 ole sauga e setiga le au’aga le fluid e ave ese ma lo’u tino, ma mea fa’apena. O le mea lena e lelei iai ia te a’u le machine lea”.

\textsuperscript{153} Samoan Translation: Emo: “Ia loa a mea la e fai mai le pepa, le tuiga ole nila male fa’aogga ga le seti ira le machine ia ae ia au a ia ote le manao ai, e sili ia au le alu pea o ia e fai lana machine ile falemai e faigata ne tei ua iai se taimi ua sese ai foi nane sata faiga le machine na afaina lea o taita se le afaina le ma’1 se pei e lelei a ia le (laughs) sua afaina taita toe afaina ma le mai ia ae lelei a le falemai ia aua lae I lugia o teine fomai pena”.

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R: Well, who wants to be driving when they’re tired you know?
Uso: Yeah, I mean, yeah, a lot of older people yeah don’t even wanna drive or anything like that, but, I suppose it would just be a money thing. I mean, I suppose they can’t have a nurse going around to everyone’s house, every time they wanna dialyse?

The factors of increased frailty and lack of confidence to insert needles and to operate equipment are issues that Uso believed could be resolved through an alternative home-based workforce.

Uso: I think everyone that could do it, or if they could do it, would do it. I don’t see why they’d want to be in hospital?...Yeah, I’ve actually thought about that too, like, thought about how many people in the unit could actually, yeah, just that kind of thing, like, actually if you had, you know, even someone who’d done training before, could even set it up for them?...I suppose you’d have to have someone trained.

5.7.3.2 Home visits and clinical support in the home

Ivi believed that home visits and regular and thorough inspections of patients’ houses would be a way of ensuring that families could be better helped. Ivi said that her own mother, who was also a dialysis patient and used to dialyse at home, was visited regularly by the district health nurse during the late 1990s. Home visits should be made a feature of home dialysis so that home-based patients can be better supported.

Ivi: ’Cause I remember Mum, a nurse used to come here, and I know it’s all about funding and things, but having someone of your own that actually if she’s dealing with renal, to actually going into people’s houses and just paying them a visit. ’Cause a lot of people are lonely, and they just need someone to talk to, and talk with, or...having those kinds of support groups in the area, especially for um, like in our area as Pacific.

Greater priority also needed to be made to help younger adult patients whose needs for greater independence often experienced difficulty with being able to integrate their other aspects of their lives with their dialysis.

Ivi: For the future, um, I wouldn’t mind also, that um, in terms of like housing and that, that they’d do it right, and that, if only, like they’re building all these new houses around you, and um, maybe prioritising, you know the ones with the health conditions, like for example with ile’s condition. I mean she’s 21 now, but it was a pretty big struggle you know through the years, and if only, things were um assessed properly, and come into your house and have a look... rather than putting, the blame on, um, people just being lazy, ’cause people do try their best, and they’ve only got limited resources to work with, or even finances.
Ivi also desired to own her own house so that she could provide her daughter with a better space to dialyse. If more Pacific families could be supported into better accommodation then it would greatly improve their living circumstances.

*Ivi:* I think future for me, I would like to buy my own house, and be able to have my own house so that, so that even for Ie to have a unit at the back of us if she wants, so that she can be able to just have her own space, and some, 'cause I know that and I understand that in our extended families, Pacific families...I'd rather look after my Dad, and my Mum, and not rely on um, caregivers, or other services out there to place them in. But just to put a unit at the back of me with something like that for le; and just understanding that our cultural size of it, even in a house, where we have for Pls, we have a lot of family, extended family.

Again, home visits are raised as an important consideration for home-based patients. It was only after she persisted with her request, that the renal unit organised a home visit by the renal physician to come to their home.

*Osi:* Yeah, I wasn't, too impressed about that, I remember ringing, and that's when they finally, someone did come out, yeah, yeah, so, you know just ensure that her dialysis is doing well, she's got no infection or something.

One of the major advantages of institutional dialysis is having the company of other patients with more experience in dialysis to share ideas and to resolve problems.

*Uso:* So, and it was really good to, um, spending that long, just meeting other patients after hours, yeah, it was really good. Especially some of the older guys that'd been doing it for a while, just, yeah, just to see all the different ways people do it. Like that guy ( ) who does it, is it 15 hours once a week, or 10 hours once a week or twice a week.

As he reflected about his early start on home dialysis, Uso had expected more than one follow-up visit and one telephone call by the renal unit and said that there needed to be more visits. For the most part, he felt that he had to fend for himself and cope with the unanticipated experience of loss and isolation of being at home alone.

*Uso:* Um, whereas, if I was in hospital, I probably would've had the nurses looking at my results, yeah, you know, telling me to change it. But that's where I think maybe just like follow-ups when you first start would be good, just even calling you every week and just asking you how it's going. Um, so yeah, that's probably the only disadvantage,
just having anyone checking up on you, or, um, if you’re not, even if you just like to talk to someone.

Talks with other patients highlighted that a few of them felt isolated on home dialysis; some spending a lot of time talking on the telephone with other patients and friends or having help from family members.

Usu: A lot of people, I know like Ie said, she talks to people on the phone all the time when she’s at home. Or ( ) the same, talk to people quite a bit, so, its, yeah, that would be easier talking to someone at hospital.

Usu felt that home patients missed out on some of the services that hospital-based patients took for granted. For example, getting one’s blood results sent to home within a reasonable timeframe should be made available for home patients. This also included other important services such as regular nutritional consultations.

Usu: Nah, its ( ), but ah, yeah, it probably be good to just talk to a nurse, about maybe you know, even just your results. Might be your um, your target weight, what’s happening with that, blood pressure and all that kind of thing, ‘cause, ah, I don’t actually with my blood test results, they’re supposed to send them out to me, but they never do. But the hospital sees them, and ah, I don’t actually know what they are, but they, they ring them if they’re bad, but, I don’t even know what’s happening with them, (giggle). They just say, “They seem to be okay”, but yeah.

R: ‘Cause you’ve got to do those blood tests regularly don’t you?
Usu: Yeah I’ve got just the monthly blood tests for full blood count, and just all the levels in your blood, the potassium and all that.

5.7.3.3 Support to employment

Usu admitted that it took a while for him to adjust to his son’s health and to accept that it had affected the way that they worked together on the job.

Usu: Yeah, because I’m far more, I, I’m, it’s, it’s quite difficult in that he works for me, and I think that I’ve always been a little bit hard on him, than I have been on the other blokes. Ah with his condition now, ah, I’m probably a bit over protective now, gone, too much the other way, but I think, I, I’m trying to find that balance where you know, if he says, “I’m tired, I’m going home”, I say, “Okay, off you go.”
Uga: And the next photo of Usu standing by the van, um, I mean, I can’t speak for Usu and his perspective on the whole kidney failure and dialysis process, but for me, that it’s so neat that Uso works for Usu and ( ), and that he’s been able to keep his job.

Being able to support his son at work drew them closer together.

Usu: Thinking that you know, his, his body is capable of doing all this (laughs) extra stuff. But um, yeah, I’m, I’m coming to realise that he, I have to trust his, um, his judgement on what he’s capable of doing, but as far as um, um, working relationship is, I think it’s, I’m appreciating Uso more as a son now.

On the job, Uso himself noticed how much strength he had lost, and although dialysis allowed him to return back to work, he, like other participants in the study, also experienced grief about what he used to be able to do before he became sick.

Usu: Um, so yeah, I’m pretty, I’m looking forward to getting back to work too, it’s um, I suppose it’s, it’s kind of a bit stink too, like, actually going to work and you know, you realize that you can’t work as hard as you used to…and that kind of thing. Especially labouring as well, you notice it a lot more… and you kind of, it’s still disappointing, just not being able to keep up with everyone else, or, keep up with what you used to be able to do.

In a photograph taken of her sewing room Emo described how she gave up her full-time job when her husband started dialysing at home on CAPD three years ago. She took up sewing jobs for her own interests and it became a good way of supplementing the household income. While it was a way of building positive social connections with the wider Samoan community Emo had hoped to return to paid employment, but was never assisted to do so.
Emo: shirts for the Fathers, was an order for our uniforms, for the Alo’a, the Aloha Night! … sewing, when an order comes from the Youth Group or the Sunday School, or something for the church, no sleep the whole night right through to the morning – no sleep, when there are lots of uniforms brought here all the time is taken up with it, so count 50 children to 60 adults, do all of it!⁵⁴

5.7.3.4 Translating medical information for Pacific families

For over a decade Ofe and his siblings accompanied their mother and father to the hospital to provide language translation. They had been doing this for more than 11 years and in all this time, they had never met a Pacific renal nurse or renal doctor at the hospital. Below photograph 7.12 of the CAPD Instruction Manual that Ofe received when he did the peritoneal dialysis training for carers at the renal unit. One of the main reasons his mother was a firm believer of home dialysis was that at home it was easier for her to be comfortable around family members. If she and other Pacific families could have direct contact with Pacific renal staff then the hospital could be a more inclusive place and make a difference for Samoan families’ understanding of dialysis treatment. Language translation was identified by other participants in the study and is an area of care that renal staff also acknowledged as being important but difficult to fulfil given the shortage of Pacific renal staff across the country.

⁵⁴ Samoan Translation: Emo: “Ofu tino ga tamā tau oka mai sa suī, ole matou togiga ole Alo’a, le Alo’a Night (smiling)... suīsuī, a aumai se oka ole autalavou, po’o le aoga aso sa, ose mea pei o le lotu, le moe le po atoa, alu ma le taeao - le moe, pe a e tele a togiga e aumai, e alu gata i le taimi e, ia a faiatu le lima sefulu tamaít i le ono sefulu tagata, fai uma!”
Ofe:  We picked up on it last year, that obviously...in regards to Mum’s appointments... at least one of us had to be there, I suppose just having a Pacific Island nurse or a staff member there just to liaise between the patient and the um, and the staff would be really good just for better communication...to put them at ah, ease too. They wouldn’t have that burden not to speak, or, just basically be embarrassed, or probably too shy in trying to say something in English, ....

5.7.4 Summary

In this section, families identified many of the difficulties they experienced in trying to maintain the formal requirements of home dialysis. Generally, families expected more home visits and assistance from the renal services for nutritional and dietary intake, training for carers and the co-ordinating the numerous external carer agencies that became involved in their cases. Elderly patients without spouses to assist them felt unfairly excluded from being able to take up home dialysis. Young patients wanted more clinical support with needle insertion especially when they were unwell and lost confidence with needle technique. Families frequently mentioned wanting to have clearly written information about the relevant services provided by public health authorities.

Taigau (Tide Broken) refers to the gradual restoration of health after a high fever. Home dialysis provides an initial period of respite for patients and their families from travelling to hospital services. This however changes as families’ resources and efforts diminish and without sustained levels of support can influence decisions to continue or to abandon home dialysis.
6 RESULTS - INTRODUCTION TO THE HOME DETENTION STUDY

This is the results chapter for the Home Detention Case Study. The first section summarises the key themes to help the reader comprehend the differences between institutional and home imprisonment. While the number of themes and sub-themes for the home detention study is substantially fewer than the home dialysis study, I decided to include more interviews that could assist give more background about imprisonment in New Zealand. This is not to detract from the participants unique perspectives but to build a more composite picture about how Pacific officials working within the prison system might have observed the way Samoan families manage the complexities associated with imprisonment. The key informants might also contribute to the study’s objectives of contextualising imprisonment, wrongdoing and its redress according to Samoan cultural capital and the domains of front, back and middle house. Two important topics that discussed by the participants and the key informants are: the key advantages and challenges associated with home detention. \(^{155}\) *Ifoga*, the Samoan indigenous apology made by an offender to an aggrieved party, was a subject that was explored in some depth as well. *Ifoga* is recognised as a restorative justice intervention within the New Zealand justice system.

6.1.2 Key Themes and Headings

The themes that emerged from the three participants' photographs and summarised in the tables in this section, highlight some unique insights about what imprisonment was like for them within the institutional and home settings. Foe’s narratives as summarised in Table 6.1, describe the harsh realities of prisoner violence and standoffs with other women prisoners. Inside the prison institution, meaningful employment gave her focus and purpose. Losing her job however, reinforces the immense frustration and boredom when she goes home for home detention and explored her prospects for employment.

For Galūa segregated status as a 16-year-old provided a shield of protection from the adult prisoners around her. None-the-less, the presence and guidance of adult

\(^{155}\) Family house, otherwise known as the “approved residential address” for the home detention sentence. Occasionally, the presentation format of the chapters shifts back and forward to the detainees in prison or at home. As a way of distinguishing the two different time frames and locations I refer to the ‘prison setting’ as the ‘first interview’ and the ‘home detention’ setting as the ‘second’ and ‘third interviews’ respectively which were held at the participants’ family house (refer to Table 3).
prisoners and family adults became an important and ongoing component of her incarceration.

In Table 6.2, the thematic analysis reveals the pressures of living with family members and adjusting to the restrictions of electronic monitoring. The perspectives of the key informants provide interesting background about other pertinent issues associated with Pacific offending, restorative justice and the relevance of family support for home detainees.

Table 6.3 presents the themes associated with the middle house in the lives of the participants and the relevance of ‘forgiveness’ and ‘respect’ as part of the healing process encouraged through cultural understanding. Several examples other examples emerge from the key informants’ stories, which compiled together with those of the participants help to highlight the real challenges of home detention as a very difficult and complex sentence when detainees have no prospect of support, rehabilitation or employment.

**Table 6-1: Section A – Foe’s Story**

| Section A – Foe’s Story  
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</tr>
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</tr>
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</tr>
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</tr>
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</tr>
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<td>6.7.6 Family graves</td>
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</tr>
<tr>
<td>6.8.8 Violence</td>
</tr>
<tr>
<td>6.8.9 Incest and chronic mental illness</td>
</tr>
<tr>
<td>6.8.10 Fa’alavelave</td>
</tr>
<tr>
<td>6.8.11 Summary</td>
</tr>
</tbody>
</table>
6.2 Home Detention Participant Demographic Information

6.2.1 Home detainees and sponsor names and offending history

This study investigated the perspectives of three participants, two home detainees named Foe and Galuā and a sponsor named Tulutulu.\(^{156}\) Foe and Galuā served institutional prison terms under the jurisdiction of the New Zealand Prison Service at Arohata Women’s’ Prison. When they were released from prison to commence home detention, they were registered with the Community Probation Service where they lived.

Initially, three prisoners agreed to take part in the study, but after taking part in the first interview, one prisoner withdrew, an option made clear in the consent process.\(^{157}\) Interviews were conducted with the detainees at Arohata a few months prior to release for home detention.\(^{158}\) The validated sponsors of both detainees were also approached for the study, but only one sponsor (Tulutulu) agreed to participate.\(^{159}\) Tulutulu was the oldest participant at 55 years of age and was born in Samoa. (See Appendix 12 summary table of detainees demographics).

Galuā was the youngest of the participants and aged 16 at first interview, although she was 15 years old when she was convicted of a crime of grievous bodily harm (GBH).\(^{160}\) Foe was aged 26 years old and was also convicted of GBH. Both women committed their offences in towns where they did not normally reside.

Foe and Galuā were first time offenders within the criminal justice system and were sentenced to two years imprisonment. The seriousness of their crimes reflects a growing trend in Pacific offending patterns in New Zealand, where Pacific people have higher apprehension rates than any other ethnic group (refer Chapter 2).

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\(^{156}\) The names of participants that appear here are pseudonyms for original identities. The meaning of Galuā is rough wave. Foe means oar/paddle. Foe are also referenced as weaponry.

\(^{157}\) The interview of the third participant has been excluded from the study.

\(^{158}\) The very small sample for this case group was due to the generally low intake of Samoan prisoners at the Correctional Prison where the study was based. The Correctional Prison that assisted with recruitment had offered to find potentially suitable prisoners from the Southern and Northern regional facilities. Had I extended the uptake of my sample group outside of the Wellington region, and taken referrals from the Southern region (Christchurch) and Northern region (Auckland) the sample potentially could have led to a larger sample size. I declined the offer because of the additional fieldwork costs and time involved in the initial and repeat visits.

\(^{159}\) Validated Sponsor: an individual that is formally approved and considered suitable to support the detainee during home detention sentencing.

\(^{160}\) My interview with Galuā and her mother Tulutulu (sponsor) was carried out on October 2006 at their home. Four weeks prior to this, I had interviewed Galuā for the first time at the state prison on 1st June 2006. I also met up with Foe on two separate occasions (10 months and then 17 months) following the 1\(^{st}\) June prison interview. Interview 2, April 2007 (home detention); Interview 3 November, 2007 (while on probation).
At the time of committing their crimes, alcohol and other drugs were contributory factors. They were required to do rehabilitation counselling for alcohol and drug abuse and also anger management as part of their sentencing plans. Prior to their crimes, neither of the women knew about ifoga as a restorative justice intervention under the criminal justice system. Galuā’s family presented an ifoga to the family group conference (FGC) in the presence of the New Zealand Police and Family Court Judge, although the victim chose not to attend the proceedings; a factor which impacted negatively on the family’s experience at court.

### 6.2.2 Employment, retraining and programmes

Prior to their crimes, all three of the participants were in full-time employment; Foe worked in the manufacturing industry and Galuā and Tulutulu did agricultural seasonal work. While awaiting sentencing (for at least six months), neither Galuā nor Foe were able to work. During their imprisonment, Foe obtained a paid job as a kitchen hand inside the prison institution but was unable to get employment during home detention. Galuā had no prospects for employment during imprisonment.

### 6.2.3 Rehabilitation treatment programmes

Finding rehabilitation programmes to complete their sentence plans was difficult. Foe was still awaiting confirmation about a counselling programme 8 weeks after release from prison. At week 36 (8.5 months), Foe was still waiting confirmation from her probation officer to be referred to a drug and alcohol counsellor. At week 72 (18 months), Foe had completed individual counselling that her family helped to find and was forced to go back to the same counsellor, who put her into a therapy group for people with drug and alcohol problems. While the group was not specifically set up for anger management issues it was the closest thing that Foe could access to complete the conditions of her sentence. Foe said that she and her family had to use their own resources to find the services and experienced delays for approval from the probation office.

At week 25 (6.5 months) of imprisonment, Galuā did not have a court approved anger management course confirmed for her. In prison she had been told she would be doing it as part of her sentence conditions, but as she was not enrolled in a course she lost her initial enthusiasm and optimism.
Table 6.2: Detainees Offending History

<table>
<thead>
<tr>
<th>Family Group</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Detainees</td>
<td>Galuā</td>
<td>Foe</td>
</tr>
<tr>
<td>conviction history</td>
<td>1st offence</td>
<td>1st offence</td>
</tr>
<tr>
<td>type of offence</td>
<td>gbh(^\text{161})</td>
<td>common assault, gbh</td>
</tr>
<tr>
<td>length of conviction (custodial &amp; home imprisonment)</td>
<td>2 years</td>
<td>2 years</td>
</tr>
<tr>
<td>length of home-detention</td>
<td>9 months</td>
<td>9 months</td>
</tr>
<tr>
<td>length of prison term served at time of interview 1 (prison institution)</td>
<td>8 weeks</td>
<td>8 weeks</td>
</tr>
<tr>
<td>detainee age at time of interview 1 (prison institution)</td>
<td>16 years old</td>
<td>29 years old</td>
</tr>
<tr>
<td>length of prison term served at time of interview 2 (home detention)</td>
<td>25 weeks (9 weeks on home detention)</td>
<td>36 weeks (4 weeks on home detention)</td>
</tr>
<tr>
<td>detainee age at interview 2 (home detention)</td>
<td>17 years old</td>
<td>30 years old</td>
</tr>
<tr>
<td>interview 3 (community probation)</td>
<td>not interviewed</td>
<td>72 weeks (36 weeks on home detention)</td>
</tr>
<tr>
<td>detainee age when offence committed</td>
<td>15</td>
<td>27+</td>
</tr>
<tr>
<td>breaches during home-detention</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>number of sentence planned programmes completed during home-detention</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>number of job interviews attended during home detention</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>able to secure employment while on home-detention</td>
<td>no</td>
<td>No</td>
</tr>
<tr>
<td>employed 6 months prior to offence committed</td>
<td>yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Offence committed within the province that detainee resided?</td>
<td>no</td>
<td>No</td>
</tr>
<tr>
<td>ingestion of alcohol or illicit substances 24 hours prior to offence being committed</td>
<td>yes</td>
<td>Yes</td>
</tr>
<tr>
<td>gang affiliation/involvement</td>
<td>yes</td>
<td>No</td>
</tr>
<tr>
<td>detainee in transit when they committed crime</td>
<td>yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

6.2.4 Housing tenure of the home detention participants

Foe had left New Zealand for almost a decade and lived temporarily in the family house that her mother owned for home detention.

Galuā was prioritised for social housing because of home detention. CPS had worked closely with HCNZ and WINZ to ensure that Tulutulu was supported to have a suitable house and location for home detention. Prior to this, she experienced

\(^{161}\) GBH: Grievous Bodily Harm
many problems with HCNZ in other rental properties she lived in. Home detention provided her the most positive experience with HCNZ that she had had as a tenant. The house had three bedrooms and Tulutulu lived there with her three-year-old grand-daughter and Galuā.

Tulutulu only single parent household was allocated a HNZC three bedroom property because her daughter Galuā (17 years old) was sentenced to home detention. Prisoners generally experience on average more difficulties in finding and securing stable accommodation, so when the Community Probation Office offered to liaise with HNZC, Tulutulu was moved to a “nice” neighbourhood and given a newly refurbished property so she as a sponsor could supervise her daughter full-time. It was “the best house” she said they had “ever” had. In previous years, she had many problems trying to get HNZC to do maintenance work on her house and to be relocated to a safer area. Under home detention, the state provided a safe location and a suitable house.

Foe (aged 27) was able to move straight from prison into her mother’s house for home detention, because her mother owned her own house. At the time of committing her crime, she had very few options of accommodation because she was living overseas. Foe’s main negative experience of institutional prison was hostility and violence; doing home detention was a far better alternative, although her greatest complaint in relation to both prison settings was boredom.

6.2.5 Cameras

The purpose of using the camera to capture the experiences of detainees’ is exceptionally rare. A disposable camera was distributed to the each of the three participants of the home detention study. One additional camera, which I was authorised to take into the prison at the time of the first interview, was used to produce the photographs that the detainees made of their former cells (Set 1 in Table 8.2). Both women were however, constrained in the photographs they could take in prison, because a prison officer and I were present when the camera was used. Another additional camera was used at the time of the second interviews on home

162 Consent to take the photographs was provided by the General Manager of the Prison. At the time of taking the photographs, each woman was required to be escorted by me and a Prison Officer. We waited outside of the cell by the door where the detainee could be seen in full view while the photographs were being taken. See Appendix 7H: Permission Letter which I was required to carry with me at all times at the prison site.
detention which I provided for the participants to make any additional photographs they wished to (Set 3). At Interviews 1 and 2, I was asked by the detainees to assist by taking a photograph that they posed for. These included one photo of Galuā in her prison cell and two at her home wearing her PID; one of Foe at home displaying the tattoo on her forearm.

6.2.6 Dissemination of the findings for the home detention study

The home detention case study, despite its small sample size provided some genuine interest from senior staff of the Department of Corrections with whom I met to present the findings of the study (see also Chapter 7.6.5.4 and Appendix 7K).

After about six months when I completed the home detention fieldwork, I met with the most senior Pacific manager at the Department of Corrections to present the photographs that the home detainees and their families had produced for the study. Genuine interest was expressed about what the study had uncovered and that I on completion of my PhD to reconnect again with the Pacific unit at national office to explore avenues of disseminating the results.

At the end of October, 2007, I met with the newly appointed Manager of the Arohata Womens' Prison. She was pleased that the former Manager had supported my study because of its focus on Pacific Island prisoners, particularly Samoan women whom made up the biggest population group nationwide, after Maori and Pakeha. After viewing the findings of the study, the Manager invited me to come back at a later time to present my findings to the Prison Officers at Arohata, an invitation I was keen to accept.

Over the following 12 months following interview, I maintained phone contact with both of the participants and informed them that I had been to the Department of Corrections head office and to the Arohata Prison where I presented their photographs. Both women were pleased that their contributions had been disseminated to policy makers who might be able to improve different aspects of

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163 On this visit to Galuā’s home, I had taken a spare disposable camera. At the end of our interview, Galuā mentioned that she had forgotten to take a photograph of the electronic anklet. I offered to take a photograph of her and she agreed to it. When I asked her whether she had taken photographs of the other areas of her house where the electric perimeter extended she said that it was only the front areas she took. She then used the camera to take photographs of the backyard fence so that it could be included in the study.
home detention, particularly with respect to training courses, counselling services and employment.

Several months after the Arohata meeting, I was contacted by the Department of Corrections and told that in order to continue further research I needed to complete a full contractual agreement with their organisation, as an extension of the approval I had received by Arohata. The contract took up to four months to complete, partly because I was on study leave overseas and partly because it had to be approved “retrospectively”. Not returning back to Arohata to present the findings of the study was a missed opportunity that I hope to rectify in the near future.

6.2.7 Participant photographic sets

Table 6-4: Photos taken by the participants

<table>
<thead>
<tr>
<th></th>
<th>Family 1</th>
<th>Family 2</th>
<th>Home Detention Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Foe</td>
<td>Galuā</td>
<td>Tulutulu</td>
</tr>
<tr>
<td>SET 1</td>
<td>4</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>SET 2</td>
<td>21</td>
<td>24</td>
<td>24</td>
</tr>
<tr>
<td>SET 3</td>
<td>4</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>All Sets</td>
<td>29</td>
<td>41</td>
<td>24</td>
</tr>
</tbody>
</table>

In total, 94 photographs were produced for the home detention. There are significantly fewer participants for the home detention case study (compared to the home dialysis study). Table 6.4 (above). Each of the participant’s photographic sets can be viewed in the Appendices: Foe (Appendix 8.12); Galuā (Appendix 8.13) and Tulutulu (Appendix 8.14).

6.3 Background of Five Key Informants

In addition to the participants’ research data, I analysed interviews with five key informants: four prison officers and one lawyer (Samoans n=4; Pacific\textsuperscript{164} n=1). This was (Refer to Table 8.3 below for information about the key informants).\textsuperscript{165}

\textsuperscript{164} To protect the identity of the participant, I have not identified the specific ethnicity of one of the key informants, other than that they are non-Samoan and of Pacific descent. Elsewhere I refer to ‘Pacific’ to include Samoan and all ethnicities of Pacific descent.

\textsuperscript{165}
6.3.1 Prison officers background Introduction to key informants of the home detention study

The four prison officers include, Tao and Maota two highly ranked and long serving senior Pacific male prison officers in the New Zealand Prison Service (NZPS) (15 and 16 years respectively).\(^{166}\) Both these informants, helped to contextualise the changes over the last two decades that have occurred to Pacific offender profiles within the criminal justice system. Interestingly, they also emphasised that, home detention is not a sentence recommended for everyone, although with respect to Samoan prisoners, the Samoan family social system can have both a negative and positive influence on a detainee’s motivation for change.

Key informants Unu and Pu’e were two female prison officers newly inducted into Arohata Prison (24 and 8 weeks respectively). The two women provided fresh insights about the restrictive realities of institutional imprisonment and some the characteristics and differences between Samoan female prisoners and prisoners of other ethnicities. They also agreed that home detention can benefit Samoan detainees and depending on the support provided by their families it can make positive changes after imprisonment.

Upu, a Samoan family court lawyer with twenty-year experience of representing Maori and Pacific offenders, has assisted many clients who were sentenced on home-detention. She has also observed the changes in Pacific offending patterns particularly the emerging differences between Samoan-born and New Zealand-born offenders. A significant issue is the diminished capacity of New Zealand-born offenders to demonstrate fa’aloalo (remorse and respect), and that this affects progress to reintegrate back into the community after imprisonment. Upu was also concerned about the complications that many female home detainees experience from spouses and family members, when there has been historical ‘domestic violence’ and ‘sexual abuse’ issues.

No cameras were distributed to the key informants, however, I took the opportunity to pre-test the visual diary with the four prison officers to gain feedback about the

\(^{165}\) It is important to acknowledge that prison officer’s roles within the prison institutional setting, are different and separate to probationary officers within the Community Probationary Services of Corrections who monitor detainees out in the community and conduct home visitations.

\(^{166}\) More information from the interview transcripts and photographic summaries of each of the justice officials is provided in Appendix 9.3.
photographic methodology used for the study. Fortunately, each of the officers expressed very positive comments and felt that the diary was a very good way of explaining the purpose and goals of the study. They were also very interested to see the results and the photographs at the completion of the study. (See Appendix 13 for full summaries of the interviews conducted with each of the key informants).

Table 6-5: Key Informants

<table>
<thead>
<tr>
<th>Key Informants</th>
<th>Justice Officials Experiences with Home Detention</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Maota PO 1</td>
</tr>
<tr>
<td>ethnicity Samoa</td>
<td></td>
</tr>
<tr>
<td>Born</td>
<td>Pacific Is</td>
</tr>
<tr>
<td>gender (male)</td>
<td></td>
</tr>
<tr>
<td>gender (female)</td>
<td></td>
</tr>
<tr>
<td>age at time of interview (years)</td>
<td>45+</td>
</tr>
<tr>
<td>professional role</td>
<td>prison officer</td>
</tr>
<tr>
<td>professional experience working with Samoan prisoners (years)</td>
<td>15+</td>
</tr>
<tr>
<td>emergent themes</td>
<td>in prison there are significant differences between NZ born and Samoan born offenders</td>
</tr>
<tr>
<td>the family unitary system is a potentially significant influence on a Samoan offender’s experience of home detention</td>
<td>agree</td>
</tr>
<tr>
<td>not enough is done to support validated sponsors and family members of offenders during home detention</td>
<td>agree</td>
</tr>
<tr>
<td>home detention is a viable sentencing option for Samoan offenders in New Zealand</td>
<td>agree</td>
</tr>
<tr>
<td>the customary practice ifoga is a viable option for restorative justice in New Zealand</td>
<td>agree</td>
</tr>
<tr>
<td>Self-internalised ‘shame’ is an important deterrent of Samoan detainee non-reoffending</td>
<td>agree</td>
</tr>
<tr>
<td>self-internalised ‘remorse’ is an important deterrent of detainee non-reoffending</td>
<td>agree</td>
</tr>
<tr>
<td>home detention can be a more difficult sentencing option than state imprisonment</td>
<td>agree</td>
</tr>
</tbody>
</table>
Section A - Foe’s Story of Imprisonment

Foe’s experiences inside of the State Prison walls

6.4 Front of House: The built environment of the prison institute

In this section, Foe describes her experiences of living in a prison institutional cell. Main living areas such as the bedroom, bathroom, and kitchen were places that Foe and Galuā used for ‘privacy’ or shared activities. Figure 6.1 (above) summarises the key experiences of Foe’s institutional incarceration, discussed in more detail in the following sections.

6.4.1 Surprised by family’s perception of the “modern” prison building

Foe said that when she showed her family four photos she took of her former prison cell they were surprised to see how ‘modern’ the prison buildings were; challenging some of the views they had about prison as a place that is ‘old’ and ‘run down’.

R: What was it like for you? To see these photos of the cell, the place where you stayed?
Foe: (Smiles) Oh, it was, a bit of a laugh… like my family, yeah my sisters and them, and just, they were, you know, was trying to explain to them you know, what it looked like …they thought it, oh, it wasn’t as bad as what they thought. Yeah, nah, they just thought, you know, I think they must, watching too much TV aye? Thinking the old grill, or (grinning, pause)...Nah, they were shocked, they thought it was quite you know,

167 Describing the women’s prison cell as ‘bedroom’ would not be accurate given that there are ablution facilities as well as bedroom furnishings and personal belongings such as clothes, books and writing materials.
it was quite nice - compared to what they thought it was! (Second Interview)

6.4.2 Bedroom at home is warmer and private

Foe served four months inside prison and then moved into her mother’s house. She had her own bedroom and the first thing she noticed about being home was that her bedroom was much warmer, compared to the poorly heated prison cell she had. Prison regulations also restrict the number of blankets a prisoner is allowed and Foe was often cold, so she improvised by wearing extra clothing to bed.

Photo 6.3 Foe’s prison bed and drinking fountain. To the left of the fountain is a toilet

Foe: But, oh, just, not as cold [bedroom in family home], ‘cause in there, you’re only allowed the old, limited, um, blankets and stuff, and those cold nights, you just go to sleep with your pyjamas and aye your jumper and that too (laughs), in the cold at nights aye you sleep, you don’t even wanna take your slippers off, yeah. (Second Interview)

Her bedroom was also Foe’s private enclosure that kept out the noises of the movements expected of a busy family household of eight.

Foe: When I first came out, I spent a lot of time like in my room, ‘cause, when I came out, the house was pretty full, my sisters, you know my sister and her kids were here and her other half. And my two, you know my two younger sisters, husband’s girls and that were here too and, just coming from you know [prison]. It just felt, it just oh, I, I, it was too much, aye, and it was, all, it was real, you know, lot of racket all till all hours, you know all hours of the morning. It was just, yeah, well, it took, you know took a bit of getting used to, was alright, you know, I just moved my TV and that from my cell to my room (laughs). (Second interview)

Photograph 6.1 shows the open entrance way of Foe’s cell, a recurring metaphor about the private and public spaces of the prison environment. In spite of the
problems she had with other prisoners, she liked spending time in the wing, rather than being on her own.

Photo 6.1 Foe’s cell view out to prison court yard

Foe:  Um, (long pause) I don’t like having that feeling of being locked in, so, I just go in there [cell] when I have to. Yeah, my family and that sent me, quite a lot of books and photos, and I got the old TV and that, and they, “Why don’t you go watch TV in your room”, I said, “Nah!” I go out into the day room and just, I don’t, don’t really like being, you know, being in there when I don’t have to. (First interview)

6.4.3  Walls of hope and worry

The walls of her prison cell were an important space to display photographs of family and friends and for “keeping (her) spirits up”.

Photo 6.2 Foe’s photo collage displayed on wall of prison cell

Foe:  Yeah nah these are just ah the photos in my cell...of family and friends...nieces and nephews. Just something to keep my spirits up, you know when feeling sad and that...just look up and yeah, you know, haven’t got my family in there but oh, you know (Second Interview).

On the first two nights in prison, she was overwhelmed with worry because her mother was recuperating from a major operation in hospital.
**R:** What was it like first day, first night?

**Foe:** Um, oh, just slept. Yeah, just, yeah, but, bit nervous. Um, oh, you know, bumming out quite a bit, ‘cause, she’s [mother] just um, oh, was, last week she went for a, for her operation, yeah, just bumming out couldn’t be out there to support her and...yeah...yeah, yes, yeah, ring my family every day to speak to them, see how they’re going, let them know I’m alright. Um, came in on the (date) 2006, just after my sentencing. (First Interview)

### 6.4.4 Girlfriend at home waiting for me

Amongst the photos were pictures of Foe’s partner of nearly 10 years, whom she lived with overseas before she was convicted.

**R:** She’s gonna wait for you?

**Foe:** Yeah...we’ve been together for about seven, eight going, eight years...Yeah, so, what’s a couple of years compared to a lifetime? (Smiling) It’s nothing! (Laughing)...Just have to think positive!

**R:** You’ve got a good attitude, aye! Yeah. (First Interview)

Foe spoke candidly about her long-term same sex relationship and the co-parenting role she shared with her partner’s daughter. Some of Foe’s family found it hard to accept that she was raising a child with a woman, because of the Catholic Church’s stance against homosexuality.

**Foe:** A lot of my other family weren’t too keen, ‘cause my partner, you know she’s gotta daughter, and, that’s, you know, we can’t be, we’re Catholic, we’re from a Catholic family, and that’s not the, that’s not the go. But, I gotta lot, I got other cuz [cousin], a lota, quite a few gay other cousins, you know, I’ve heard the way they’ve gone on about them.

She persuaded her partner to wait until her prison term was over before making a decision about whether to move back to New Zealand. Members of her immediate family cautioned Foe to be discreet in relation to her sexuality. Her siblings and mother were not “shocked” that she was in a relationship with a woman; but they were concerned that other family members would not be as tolerant or accepting about her gay identity and lifestyle.

**R:** You seem um pretty out there in your sexuality; do you wanna talk to me a bit about that?

**Foe:** Like with my Mum she chooses, “It’s - that’s your business”...But, with my Mum and sisters, “Well, if you’re happy”, you know, “It’s alright, but, you know don’t put in their face!” I don’t put it in their face you know, my Mum she’s pretty placid and she doesn’t really say much, but, yeah, nah, she’s, doesn’t say it, but she’s pretty cool with it, yeah you know.
As will be discussed later, in prison, Foe intentionally exercised discretion about her sexuality and or discussing with other prisoners that she was in a same-sex relationship.

6.4.5 Stand-overs in prison bathrooms

Public spaces used by all prisoners such, as communal showers, toilets and day rooms had become places where Foe encountered threats and standoffs.

Foe: … Oh my mate said, “Some of the girls are eyeing up your gears” and when I was putting out my washing and one of them approached me in the shower…one was standing at the door (pause) trying to do the old stand-up. Oh, they wanted my track pants [I] said, “Oh, come and grab, come and get it then!” Then we had a bit of a, yeah, had, had a bit of a scuffle. I ended up getting the better of her. Then her mate tried to jump in. Then ah, I think, and then my mate, my old school mate come in and just let me have a go with that. You know pulled the other chick, let me have a go at the other chick, and [I] just said, “Fuck, I’m not here for this shit!” (Prison Interview)

One day, her phone card was stolen from her room and Foe blamed herself not taking enough care to protect her valuables from the “thieves”.

Foe: … This one chick that took my phone card I left in my room … and she just said, “Oh, one of them had told me who it was”…Yeah I went to the shower and came [back]. I was stupid I shouldn’t a just left it, yeah…well, I ended up going to work, and I came back and she had gotten it back, but it didn’t, ah, it didn’t get physical, she just said, “Oh, don’t leave your stuff lying around! ” (Laughs)

6.4.6 “Feral chics!” Prison sexuality

In an environment where no structured programmes were provided, she was forced to put up with what she described as the ‘animal-like’ antics and hostility of what she sarcastically described as the “under class”. As mentioned earlier, losing her full-time job in the central kitchen resulted in more than the loss of a job she enjoyed doing, it meant spending all of her time in the wing with other prisoners.

Foe: Yeah it was a bit oh, you know, feral, no class, chicks in ( ) Wing, you know (laughs). Oh, you know we just had, oh like I ended up getting into a bit trouble, but, oh, think it was like, you know, there was, you know, no other way you know around it, trying to do the ignoring, or you know, just a lot of, all this jail…(Interview 2).

168 Gears: property or belongings owned by the prisoner such as clothes, jewellery, shoes.
169 Phone cards are high currency for prisoners.
Foe said she tried to ignore a lot of the pettiness that was rife in the wing; however, it annoyed her that many of the women showed very little maturity.

*Foe:* Just, oh, too much riff raff, it’s like, it’s like being at primary school again, some of the women in there, was, yeah, just, ya had ta bite my tongue a lot…yeah, dramas, just, a lot of immature, dirty little hoes in there. That didn’t, ah, [I] didn’t find funny (grinning).

The most insidious issue she had to deal with was the unwanted flirting and sexual innuendos. It forced her to be assertive and at times more aggressive than she wanted.

*Foe:* Yeah, oh, but oh, trying to keep my hands to myself (fists posed to punch). And just, yeah, just had to do a lot of ignoring and just walking away, you know.

*R:* So you were approached a few times? Is that what you mean?

*Foe:* Yeah, you know doing the old ah, “Oh, do you wanna hook up?” [I] says, “Ah, the only hook you gonna get is my left hook, if yous don’t fuck off!” (Laughing). Yeah, but, nah, it was, yeah, oh, was enough to scare someone straight (laughing)!

In a place where security and surveillance was of upmost priority, Foe lost confidence and trust in the professional staff; a disappointment that extended to probationary staff who monitored her on home detention.

*Foe:* ...Some of the guards, some of them is really nice, but you know, I just think oh well you treat people like how you want to be treated. And you are nice to some of them, and they’re just, “Oh you’re a fucken idiot, you’re fuck...,” and hello... “Are you a guard? Or are you one of the inmates?” And then I don’t give them the satisfaction. I just ignore them and then, it’s like they get a bit, you know, trying to get a bit out of you and test you and see if, but oh, not that stupid (smiling)!

Prison had made her reflect about the consequences of her crime and often she felt deep regret about the moment when she made the fatal choice of being at the wrong place at the wrong time.

*Foe:* Yeah, we wouldn’t have walked off alone…. the you know the confrontation wouldn’t of happened (pause, reflective).

6.4.7 **Sacked from her prison kitchen job**

At our second interview, Foe had completed a month of home detention and was waiting to hear back from her probation officer about available counselling and job

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170 Hoes as in whores, sluts and prostitutes.
training options that were in her area, as it was important for her to try to find paid work. The last job she had was in the prison institution’s central kitchen. It was the most positive experience she had in prison and she was happy to have meaningful work for most of the time that she was there. However, it ended badly four weeks before she was due for home release, because she was sacked for getting into another violent altercation with another prisoner.  

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Foe: …I got the sack, so, being stuck in the wing that was real you know…She [other prisoner] came in, she’d [said], “Yous fucken ate my [food!]”…yeah, she was losing it.

R: Did she get sacked as well?

Foe: Nah…she was really over reacting and we were just laughing, she … got shitty with us…she goes, “Did you see?” I go, “Nah, it wasn’t me.”…She just went off her head and she grabbed my, um, oh, her coffee mug and threw at, like threw it at me! Oh, I just got up… and I punched her…she was ranting and raving… (Second Interview)

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Without meaningful work and without access to educational programmes to occupy her time, she was confined to the prison wing, and much worse, confined to the negative attitudes of the other prisoners.

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R: When you stopped working, what was it like?

Foe: Oh, with the um, you know, the unemployed lot! (Laughs)

R: (Laughs).

Foe: And it was like, oh, just sitting round, oh, they just, annoy, you know, everyone’s just scabbing, or trying to steal off you! (Third Interview)

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This experience in prison was important while she was on home detention and when her probation officer failed to provide any help with ‘job hunting’, Foe’s family network approached two different factories about vacant positions for an experienced and highly skilled specialist machinist. There were positive responses and Foe was invited to both factories for a job interview. However, at one factory, a few employees, relatives of the victims that Foe assaulted took their concerns to the employer about Foe working there. When Foe found out about what happened, she turned the job down, because she had doubts about her safety in an environment where people mistrusted her around dangerous machinery. She also offered a job at the other factory on shift; however, without reliable transport and not knowing whether Corrections would allow her to go to work at that time of the night, she decided to decline the position.

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171 The incident occurred with another prisoner who accused Foe of removing food that had been prepared and stored in the refrigerator for a special function in the prison on that particular day.

172 Scabbing: begging, asking, demanding, manipulating
When I interviewed Foe for the last time, she had nearly completed 8 months of her ten months sentence of home detention, but there had been no further advancement in terms of job search assistance from her probation officer. In the duration of her home detention, Foe said that she probably could have completed a correspondence computer introductory course, but she had no confidence to find such a course after her probation officer told her to go through the yellow pages. Her positive experience in the prison kitchen, albeit the unhappy ending, would be the only time Foe felt no stigmatisation as a detainee within the workplace. As soon as she became unemployed she was treated with minimal respect by those around her; an experience that continued on home detention when she was not formally supported by Corrections into paid work.

Foe: I’ve met some really nice people but, just at work (in the central kitchen)... That’s, what it feels like and you know, just being spoken to like you’re, you know, a peasant (laughing) or you’re a nobody!

6.4.8 Foe’s Experiences of Home Detention: Back of House

Home detention at the Back of House

Figure 6-2 summarises Foe’s time at home and how she used time. Whilst, many of the activities are associated to the back of house, several of these tasks have positive and restorative effects on her familial relationships; gendered relationships, feminine responsibilities, family graves and ‘fa’alavelave’ are underpinned by cultural
capital highlighted earlier at the middle of house. These within Samoan families have positive implications to home detention and resettlement.

6.4.8.1 PIDS – the annoying ankle bracelet

“Home” in relation to home detention legislation is referred to as the “area of probation”, the “home detention residence”, “approved address” and the “curfew address”. A house or property (residential flat or commercial business) that is legally sanctioned for home detention, places the ‘detainee’ (a person sentenced to home detention) under the jurisdiction of the “Chief Executive of the Department of Corrections” (103).

An essential part of home detention is the Personal Identification Device or PID and Foe and Galuā were each fitted with one.¹⁷³

\[
\begin{align*}
\text{Foe:} & \quad \text{These photos are just of um, accessory, of, I don’t know, what they call it, a band?} \\
\text{R} & \quad \text{Bracelet?} \\
\text{Foe} & \quad \text{Ah, yeah, a detector! (Laughs)}
\end{align*}
\]

Wearing the PID caused both women some physical discomfort. Foe asked her probation officer if she could have the PID readjusted (Photo 6.3) and described having a “white mark” around her ankle when the device was removed; the same kind left on one’s wrist after “wearing a watch” for a long time.

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¹⁷³ The Personal Identity Device (PID) which is also known as the ‘bracelet’, ‘anklet’ or ‘tag’.

Photo 6.3 Foe’s PID (side view)

\[
\begin{align*}
\text{Foe:} & \quad \text{Oh, at first, at first it was quite annoying, ‘cause getting caught in the blankets or just when you’re sleeping it rests on your ankle. You just gotta pull, you know like move it around, so usually, the first couple of nights are pretty uncomfortable then you just get used to it}
\end{align*}
\]
6.4.8.2  A new coat of paint for the “ugly” electric fences

Another important function of the HMU is that it generates an electronic perimeter around the surrounding areas of the participant’s houses. All of the participants produced photographs of the landmarks that formed the electronic perimeters of their houses which included vegetation, trees, fences and letter boxes (Foe’s Photos 6.4). Interestingly, both detainees used the word “ugly” when they described the invisible boundaries that set off an alarm at a distantly remote security office if they walked over it without prior permission of the Corrections department.

Photo 6.4 Electronic perimeter to the edge of footpath closest to mailbox

Weeks prior to her return, Foe’s uncle and brother-in-law carried out some repairs to the back fences (Photos 6.5 and 6.6). She and her nephew spent time in the sun finishing off the repairs and painting the “pretty bare” and “ugly fences”. She had to negotiate with her mother to get money to purchase paints and beverages to reward her work crew.
Foe: ‘Cause I had to get the sander and scraper out, ‘cause it wasn’t a new fence, it was an old fence, so I had to get all the old paint off so, it was half the size, but.. Yeah, I did a bit of painting…the other fence. Oh, you know, Samoans, aye? Doesn’t matter, as long as its new and its paint! (Laughs)

R: So the fence line is the boundary [of the electronic perimeter]?
Foe: Yep up the side of the house …yep, and that’s the other side of the fence… (Laughs) I thought, give a coat of paint, yeah, so, it was good two days.

The anterior window panels of the house also got painted. Beautifying her mother’s house was a job she enjoyed doing on home detention.

Foe: Had to scrape all the old paint and that off…got my nephews to do a bit of painting on the windows on the outside (laughs).

One built structure on the property that Foe was warned not to enter at any time was the umu. Tests showed the electronic signal to the HMU was very weak and this caused by the galvanised corrugated iron cladding of the umu’s walls and roof (Photo 6.8).

Foe: “Oh you can go outside, but that means you can’t go in (the umu).” Oh when I…went out on my recreation night …I knew I was supposed to come back home, so I just stayed out in the car at the front, and they had detected that I hadn’t gone into the house.
On home visits made by her probation officer, Foe was surprised to be told that the security company (Chubbs) recorded the small distance between the front door and the car parked at the front of the house, where she had crossed the electronic perimeter and caused a signal on the HMU.

Foe: I said, “Oh... I forgot you know a few things and I had to come back and get it”; and that’s where I knew where, well, the bar could go across...like I had to run... my little nephew he had run out... of the car and you know I had to go and grab him...so they can detect you there!

6.4.8.3 Weeding out the garden and the boredom

Below is a photograph that Foe took of her mother’s Lilly flower garden at the front of the house (Photo 6.9). Gardening helped to relieve the major boredom that Foe experienced on home detention; boredom was something she had not anticipated when she explored it as an option for sentencing.

![Photo 6.9 Lilies at the front of the family house](image)

R: (laughs) Oh so you were doing the front?
Foe: He (Uncle) was weeding the other side...and said, (laughs), “Oh your mum’s not gonna be happy”, and I said, “Oh, well...”, and he says, “See what you say when she comes”, and then when she came, he walked down the side of the house... he went the other way he was laughing. (In quiet voice) “Oh, were you trying to blame it on me?” (Laughs).

Similarly to Galuā and her mother, Foe had casual banter with her family in relation to her experiences inside of prison. It was a welcome relief and acknowledgment of her circumstances within the family.

Foe: And he [Uncle] goes, “Oh, well,” you know, “makes your days go faster aye?! You'd be doing that if you were being inside [prison] aye?
Probably be cleaning, velo their vao (weeding) up at the jail", I said, "No, no! I don’t do that up there!"

\( R: \) (Laughing)

Occasionally her mother teased her about the gardening and maintenance jobs she carried out to beautify the house; a way of acknowledging Foe’s hard work.

\( Foe: \) She’s (Mum) not really a, you know, out, outdoors…She said, “Oh, you’re home, aye?” They must think I’m their house maid! I said, “Oh, you’re home, you do it!” Yeah, that’s a laugh!

Photo 6.10 is a close up shot of the Lilly flowers and a poignant metaphor that of the warm connection that developed between mother and daughter.

Photo 6.10 Foe’s mother’s Christmas Lilies

\( Foe: \) Oh, last surviving flowers in the front (laughs). My Mum’s famous lilies… oh, she was a bit heart broken, you know, she reckons her Christmas lilies won’t grow back ‘cause I pulled them all out (grinning)…they’re white ones…’cause when I pulled them all out, she, was, oh, yelling and carrying on. I was blaming it on my Uncle, and my Uncle was blaming it on me, ‘cause he was mowing the lawn!… yeah, she’s always bringing in little you know, those little bulbs and that, of, ends of plants… yeah cuttings and stuff.

6.4.8.4 Cleaning the earth oven (Umu) and reordering gender imbalances at back of house

After a few months of settling at home, Foe decided to do a major clean up the umu at the rear of the house. The umu was frequently by local Samoan communities since its construction in the 1980s, to prepare and cook traditional foods for large communal gatherings like family weddings (faipoipoga), building dedications (umusaga) and funerals (maliu). The gendered arrangements associated to umu and traditional cooking is mostly a male domain of responsibility. Foe’s mother often found it difficult to refuse requests by ‘outside’ groups to use the umu. When Foe
moved home, she saw that there were dynamics which affected her family's privacy and it had been this way for many years.\textsuperscript{174}

\begin{quote}
Foe: and it …looked like the ol’ Mongrel Mob pad at the back there (laughs) with all the rubbish!
\end{quote}

To Foe, the umu was a “mess” and an “eyesore” and often described it being like the “ol’ Mongrel Mob pad”. It was her way of emphasising the disorder and untidiness made by those from the outside community who had used it.\textsuperscript{175}

\begin{quote}
Foe: Oh, people wanting to come and use it and leave all their rubbish, and just, not caring, you know, “If you’re not gonna respect the household, well, go do your umu somewhere else!”…It was just terrible at the back, all the rubbish…
\end{quote}

Another key issue about the umu was the constant movement of men around the house. Foe decided that they needed a better system and initiated discussions within the family as the 'eldest sister' living at the house.

\begin{quote}
Foe: … But then when I stayed here, it was different 'cause you know it was like, you get, gaww, you know stuff putting up with this shit!
\end{quote}

The first decision involved cleaning up the accumulated rubbish; the second, how the umu should be operated without causing inconvenience to the all-female household.

\begin{quote}
Foe: When you do umu, it’s from early hours of the morning you know, just, I don’t know if it was just me, just you know, just having a lot of blokes and them around; coming in and out of the house with my sisters and
\end{quote}

\begin{footnotes}
\footnote{174}{Foe’s household included herself, mother and three sisters.}
\footnote{175}{It is an expression often employed by Samoans as a derogatory description about gangs generally and the anti-social associations with them. It can also imply racist sentiments against gang members, particularly Maori who make up a large number of the Mongrel Mob nationwide.}
\end{footnotes}
my niece here - no males being here. It was different if it was like my uncles or family... even though they say oh its church people, but oh, I don't know, they're the worst (laughs)!

Foe questioned whether the umu’s physical structure was safe to use and stressed the decades of overuse and deterioration. The main person she had to convince was her mother.

Foe: …You know with mum, I was like, “Oh look it’s gonna, it’s not safe”, or you know, she goes, “You know, what am I gonna say!” And I say, “Oh, well look, you know the poles are...no good, the poles are rotting!” Or my uncle, her brother in-law, he’s like their President of their Au lotu (church) or whatever. I just said, to him, “Oh you know, it’s not safe, you might [be] doin’ an umu and it’ll collapse on you!” Where with them, it’s you know, “Mum has the last say.”

When her mother finally agreed, the younger men in the family were again called to come back to help.

Foe: I got like my cousin’s boys, got them to come and I just did little bit by little bit. But, I you know needed a trailer to get rid of most of the rubbish (laughs).

Foe expected resistance, especially from the senior men of the family who were shocked to hear that the umu rocks had been removed from the site.

Photo 6.12 Umu stones removed from earth oven pit

Foe: This [umu] is gonna get busted down soon! “Oh, what a waste!”, and I said, “Oh, nah, (pause) no there’s no man here to do the umu! And also, there’s no use having a umu here!” And he’s like, “Oh, but you know when we have our... [Future events]”, and I said, “No, no, get a spit, get a spit!” (Laughing). That’s when, “Hire the spit!!”… You know, you get the odd hints from uncle and them, I said, “Oh well, this one’s out of [action], he goes!”
Accepting their defeat, Foe’s uncles and cousins found another location to build a new umu, but shortly after there was news that it attracted rodents. This fuelled another debate to reopen the original umu pit, but Foe was determined to stand her ground.

Foe: Yeah, yeah, the more they wanna, “Oh, we’ll come and do our umu, oh, ’cause there’s too much rubbish over there and there’s mice and that there!” And I said, “Yeah, it’s probably ‘cause yous probably treat it like a shit hole like yous did here!” “Oh, no!” You know how Samoans they just blame, “Oh, but, it, it was the autalavou (youth group)!” Or, “It was, you know those young fellas!”

R: (laughing)

Foe: And I said, “Oh well, no use shifting the blame!” It was like, “Pass the buck, and pass the buck. Oh yous are all the same!”

Reorganising the umu was important for Foe on many different levels. Firstly, it changed the gendered arrangements at the family house and restored order back to the female household. Secondly, it had helped Foe to re-establish her status as the eldest daughter, after many years of absence from the family. Thirdly, it brought Foe and her mother closer together, thus achieving one of her key goals for home detention.

R: So they really wanted to come back again?

Foe: Yeah, but, I think oh, like you know, my Mum’s happy, I just, like with us, Mum just gets me, we all pretty much got a you know, good sense of humour, just laugh about it you know get smart, and, oh, I said, “Yep, I think this family must’ve thought,” you know, “must’ve thought they were Mauli instead of [Samoans]…!” (Laughing). You know, like, my Uncle goes, “Yeah, it was pretty bad down there!”, and I said, “Oh, well, that’s the end of that now, no more!”

While Foe’s ability in this case showed leadership and initiative, it contrasts strongly to the experiences she had at the central kitchen of the prison where she used to work as a kitchen hand.

6.4.9 Summary

This chapter begins by highlighting the way ordinary houses are adapted into ‘electronic prison homes’. A recurring theme for the participants is dealing with the ‘visible’ and ‘invisible’ aspects of home detention. Outside physical landmarks such as fences, mailboxes, trees and surveillance equipment such as PIDs and HMUs are

176 Mauli: Maori. A humorous but derogatory slur connected to the earlier comment about Mongrel Mob. The expression is associated to messiness and disorderliness.
the visible objects and geographical sites that are reviled and appreciated; painted and beautified; cut down, ‘crossed over’ or breached.

Taioalo (tide-of-children) reflects the paradoxical nature of home and institutional imprisonment, where houses and prisons that are seemingly ‘ordinary’, have walls, bedrooms, kitchens and bathrooms that contain and restrain those who live within them.

Foe cleaned and dismantled the outside kitchen (umu) to restore the house to the women of the family and changed the wrestles dynamic that was associated with ‘men’s work’ at the back of house. Cleaning the umu not only helped to reorder the gendered arrangements, it made the home setting an important place for Foe to reconnect with her mother and to exercise her authority as an elder sister. Working in the kitchen at the prison institute made incarceration for Foe more meaningful to begin with, but unemployment exposed her to an environment of boredom and pettiness. Unemployment should not have been an issue on home detention, since Foe had two job offers. However, she was stigmatised as a detainee by people who knew the crime she committed and so it made it impossible for her to secure meaningful work.

The only ‘indoors’ photographs from Foe’s total collection were four taken of her former prison cell during the first interview. Her other 21 photographs were ‘outside shots’ taken at her home during home detention; she made no photos of the ‘interior’ of her family home. The photos she made outside were mostly of the maintenance activities she did at home such as gardening and painting (n=7). Only Foe took photographs of family graves (n=6) and a tattoo. Like Galuā, Foe said she “forgot” to make a photo of her PID as well as the ‘electric perimeter’ around the house. Further details about the aggregated themes of the photographs can be found in Appendix 9.1 and in the key informant profiles Appendix 9.2.

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177 This visit to Foe’s home was to collect the disposable film camera to be developed. I had asked Foe if she had used up all the film. She told me it was difficult for her to come up with ideas about what to shoot. She said that she had thought about taking photos of the backyard fence she painted and of the umu that she cleaned up. I then encouraged her to go ahead and take photos of them so that they could be included for the study. While outside, Foe showed me the fence perimeter that was electronically monitored and it had occurred to her that she did not have pictures of the electronic anklet on her leg. Foe asked me to take a photo of the anklet and agree to my suggestion to take a photograph of her Samoan wrist tattoo because it had been a topic she shared about during our first interview when she was in prison.
Section B Galuā’s Story of Imprisonment

6.5 Front of House: Life on “Segregated Status”

Galuā’s photographs and experiences of the prison institute are foreshadowed by her ‘segregated status’ as a 16 year old; a central feature of her five-month incarceration. As both a preventative and protective measure, segregated status prohibits prisoners under the age of 18 from integrating with any adult prisoner over the duration of their institutionalised term. Figure 6.3 summarises Galuā’s experiences and activities in prison, her enjoyment of being able to write, study the bible and attend prayer circle helped ward off the pervasive effects of boredom and isolation.

Galuā  Yeah, here makes you think a lot. I’m only 16, and get locked, ’cause of my age I’m locked up 23 hours and I get one hour out... 178 (Prison)

On her first night in prison, Galuā described “the bed hard” and the cells “cold”. Mostly her thoughts were of her co-offender/boyfriend who was imprisoned at another facility. Galuā met him when she was 15 years in an urban street gang; she referred affectionately to him as “my dog.”179

R:  And so what was it like your first day or first night in [ ] Prison?
G:  I prayed a lot.
R:  Yeah?  How come?

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178 Galuā was 16 years old when she entered the prison institution. By statute prisoners under the age of 17 are categorised with Segregated Status (or Segs as it is referred to by prisoners and staff).
179 Dog is slang expression to denote intimate friend, partner. It can also connote ‘dominant’ or ‘significant’ person with associations to a member of a gang.
G: It felt kinda weird not sleeping in your own bed, I felt cold. I had to wear this nighty. I’m worried about my – (grinning, shy) my co-offender, he’s in [ ] Prison... he’s still on remand...

R: Did you both offend down here in [City]?

G: Yeah (quiet, looks down). (Prison)

6.5.1 Comforted by the advice of older prisoners

The influence and interactions of ‘experienced prisoners’ on ‘first time offenders’ is monitored closely by prison officers as an aspect of prison life when prison institutions were established in New Zealand. It follows the age long concern and recognition that the prison environment is a place that educates prisoners into more advanced criminal activity. For those who are new to offending, probation and community placement is a far more humane and effective measure of punishment to institutional imprisonment (see Chapter 2). Maota was in favour of ‘segregated statuses’ as an appropriate option for young prisoners like Galuā.

R: About suitability, you said that there are some people who if they went to prison wouldn’t be very worthwhile, what do you mean by that?

Maota: Well, especially if its first offenders, they have quite um, what’s the word, ignorant?

R: Naïve?

Maota: Naïve about all the other things that happen, especially first offenders. And to bring them in under that situation and allow them to mix with all the ‘experts’ inside, it may be a downfall in the whole system, yeah, so they go out there and do it better, yeah (laughs).

Understandably, one of the things that Galūa’s mother Tulutulu worried about was the influence of older and experienced prisoners on her daughter.

R: Why is it [home detention] good for you?

Tulutulu: The reason why I like home detention as I’ve seen it is my daughter’s here, right? They’re not inside [prison], you know, because I know there’s some other problems that I’ve heard of, like smoking things that’s not allowed inside, but in my opinion, this thing [home detention] is useful especially for younger people if it’s carried out with the young ones...because they’re exposed to things beyond their age and maturity. So they should come out to do home detention, and if they commit another crime, then they should be locked.

According to Galuā the older prisoners she met helped her to think more objectively about herself and her problems. The photograph below of the “dream catcher” (wall hanging) (Photo 6.13) was a gift from another older prisoner whose adventures overseas inspired Galuā to think about travelling abroad and moving to Samoa.¹⁸⁰

¹⁸⁰ Exchange of goods between prisoners is permissible as long as there is no money involved. Because a prisoner can have a fixed number of items in their cell, all excess items is kept in storage in another part of the
Her private and discreet discussions with older women prisoners also made her contemplate getting a qualification and investigating a performance arts and tourism course as part of her home detention plan.\textsuperscript{181}

![Dream Catcher - a gift to Galuā from an older woman prisoner]

Photo 6.13 Dream Catcher - a gift to Galuā from an older woman prisoner

Galuā 18 months, but I only do half, that's nine months. So, I really looking forward to going back home and my mum. And, that I've gotta, when I go out there and make the most of my life. I’m not at school anymore. The arts course, that [try to help] get me into a great job – it's behind me [crime]…Um, I left school at 4th form and I started at a performing arts course…I wanted to do travel and tourism. I don't know if I'll go back to performing arts, or…Oh, 'cause my, part of me wants to travel the world…I wanna go to Brazil. [Prison Interview]

In an environment where the ‘66% rules’\textsuperscript{182} made her ineligible to any counselling programmes Galuā was extremely receptive to the advice of the older prisoners.

One of the key issues for Galuā was the anger she had towards her mother.

\begin{tabular}{ll}
R & …When you were inside [prison] you talked a bit about your mum and your relationship? \\
Or & Do you remember? \\
Galuā & Yeah. I, we weren't really; I wasn't getting along with her. \\
R & You were quite worried about home d? \\
Galuā & Yeah, coming home, listening to her [mother/sponsor] blah, blah, blah, but yeah.
\end{tabular}

Before she went home, she made a decision to improve her relationship with her mother and credited this to the advice that she received from an older prisoner in her wing.

\textsuperscript{181} 'Segregated Status' is difficult to enforce if a prison officer is not in close proximity to the prisoner. Often, especially at night time within the wing, conversations 'through the window' can occur which is what happened in Galuā's case.

\textsuperscript{182} 66% Rule: a detainee is eligible for Corrections educational and rehabilitation programmes if serving a sentence of two years or more. Those on short sentences of less than two years are not eligible for institutional and community-based Correction programmes.
What happened for you to change?

‘Cause, of jail [prison], the people in jail, they, oh, you know, I told most of them about how I didn't wanna come home. But they were just telling me, “Oh when you go home, treat your mum like the queen and you know, listen to her. Do whatever she wants; even though it makes you angry, you just do it!” (Giggles).

Who told you that?

Um, one of the girls inside, yeah.

So you thought about it?

Yeah, I did, every time I was in, oh, like every night I was lying on my bed in jail, that's what I think about coming home. What would it [home detention] be like? (Pause). Yeah, and then I came to the conclusion that I have to make an effort, yeah, but it's been alright, yeah. (Home detention interview)

Galuā’s experience of prison is a stark contrast to what Foe experienced. Given her segregated status from the rest of the prison population and the close supervision of prison officers, Galuā was protected from the turbulence that existed within the prison institution.

6.5.2 On the Outer Circle

One of the few activities that Galuā was permitted to do was attend the religious services that were held at the chapel each week. She enjoyed being able to listen to the music and to the sermons but felt excluded from everyone that was there. The only way that Galuā could attend the services was to be seated far away from the other prisoners. Being excluded was one of the enduring difficulties of incarceration, even at church.

They do services, but I'm not allowed to attend ‘cause I’m Segs [Segregated Status]...I sit in the office with the officer and I listen to them...Yeah, um, (laughs) wish I could like you know, be in the circle (giggles). (Prison)

Galuā’s Bible

Religious faith had always been important in Galuā’s family and while she was in jail, her mother/sponsor (Tulutulu) and members of the extended family maintained a
weekly vigil prayer circle at 3am. Going to church on Sundays was one of the most enjoyable activities she participated in.

Galuā: I went up to the thing [pulpit] and the prayer... He [church pastor] only just gave us little book, it was like a bible... At night I'd just finished getting a - being bashed.

R: Why?

Galuā: My sister she lied then she blamed it on me, and, and he [father] - must of got angry and yelled at her and then he [father] hit me with the stick (laughing).

6.5.3 “Lonely, but room to think, to write”

Galuā had been at home for two months on home detention when we met for our second interview. We talked about the 11 photographs she produced of her prison cell with the camera I gave her.

Galuā: It's like, can't believe that I was there! (Pause).

R: How come?

Galuā: Just weird feels weird, like coming out of jail and coming home; and then looking back at it, it's like, "Did I do that, did I go there?" Um, um, (long pause).

Above, a photo of Galuā’s door (Photo 6.15) and a sticky label that she placed onto the door with her name and cell number. Near to her room, an on-duty prison officer was assigned to ensure that she was kept separated from the adult population. Photo 6.16 Galuā poses for the camera to make a picture of herself inside her room at the prison.
She spent a lot of time looking at one particular photograph (Photo 6.17) of the wooden desk in her prison cell. It was here that she spent a lot of time creating music lyrics and poems. The desk was a special space for solace and for writing.

R  Which picture strikes you the most in there?
Galuā  The my desk (smiling)...‘cause that’s where I always used to sit in there, every night, writing or reading (pause). Kind of miss it (laughs). (Home detention Interview)

She used to watch the activities in the wing from behind the window and occasionally she disregarded the rules’ about not talking to the other prisoners.

Galuā  Hard aye! I look out my window and see girls, you know, talking and you know, actually walking around the lengths of my cells, you know, (giggles), think that I wanna be out there you know walking out there and all that (laughs).(Prison)

6.6  Back of House: Life on Home Detention
6.6.1  Embarrassed to wear bracelet in public

Galuā said she could feel “it” (the PID) “all the time” and it “annoyed” her. While she was inside prison, she often imagined what it would feel like to be seen wearing one in public and thought that she would probably wear “long pants to cover it up”; an indication that she was embarrassed by the idea of it.

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183 Galuā had to wait for three months before could attend the course. This would have been enough time to become accustomed to wearing the device.
If you were to change anything about your home detention, what would you change?

Galuā: (giggles) How far I can go (giggles)...To the shop and back (giggles) yeah, um (pause) but, everything is good on home detention, at least you're home, you know.

PIDs are set up and operated through a Home Monitoring Unit (HMU) Photo 6.19, a machine installed at the detainee’s residence. Galuā’s machine was kept in a kitchen cupboard next to the phone line; she took it out to photograph it. On the HMU, her probation officers made unscheduled telephone calls to Galuā, another important aspect of home detention and part of the monitoring regime.\(^{184}\)

Galuā: I can only ring my probation officer, and it has four buttons. It has emergency, for like, if you’re gonna go out of the house for emergency, like to go to the doctor. And end call and answer, you pick up, you have to push answer; when you hang up you have to push end, just like a cell phone but with no numbers.

6.6.2 Can’t go to the shops, can’t work

The PID, or the “thing on the leg” mea ile vai, in Tulutulu’s view was a very important part of home detention, because it deterred and restricted her daughter from leaving the house. It was not until surveillance equipment was installed that it affected her own movements as a sponsor. She was unable to leave the house as was she used to doing. As a parent and sponsor, she felt responsible and made the decision to be...

\(^{184}\) Galuā said that she had two probation officers over the period of her home detention sentence.
at home as much as possible to encourage her daughter’s progress. The ordinary household errands and not being able to go to the “shops”, was something she had to adjust to, as well as relying on close friends to help her out for groceries and travelling to appointments. Given the serious nature of her daughter’s circumstances, Tulutulu also felt compelled to give up her seasonal paid work. She knew that having to deal with a young person’s confinement, frustration and moodiness would not be easy.

Tulutulu: “Oh, you can’t go!” Then that’s when I know that she’s fed up! That’s the word, had enough! Even listening, had enough! Fed up with what’s going on, and then there’s all the times I say, “You’re not listening! And now it’s coming right back at you! (Laughing). I say, “Well, are you really happy now with what you’ve done or you’re not happy?”

6.6.3 Bracelet forces her to stay home!

In many ways, Tulutulu had completely embraced home detention because of the ‘control’ it gave her as a sponsor to take care of her daughter. She wanted to make the most of the opportunity to instruct and reinforce positive behavioural changes, while there was time to do so on home detention. Previously it was difficult to deal with disciplinary issues, because her daughter was a ‘flight’ risk as a habitual ‘run-away’. With electric monitoring Galuā had to accept the consequences of her wrongdoing and was forced to come to terms with issues that she could no longer run away from. The key person that could to do this with her was her mother and sponsor, Tulutulu. Consequently, Tulutulu had no outside resources to help her supervise her daughter, an aspect of home detention that she was not concerned about, because she felt that it was her prime responsibility as a parent.
R: So do you think the bracelet, the home detention makes her stay home?

Tulutulu: She should think, should really think properly about it, is it good, or not good, because this is what her life is like now, if we look at how young she is, but that’s why she has to stay at home now, isn’t it?!

6.6.4 Ugly tree! Beautiful tree

At Galuā’s house a large apple blossom tree formed part of the electronic boundary. She often suggested to her mother to have the tree cut down; she said she was ‘joking’ but it was one of many ‘ingenious’ ideas she had whenever she got bored during home detention. Shown below are two similar photographs of Galuā (Photo 6.21.29) and Tulutulu (Photo 6.25).

![Photo 6.21 Galuā’s picture of the tree that should be felled](image)

Galuā: And this is where, (giggles) I’m not allowed to pass!
R: The tree?...What do you think about the tree anyway?
Galuā: Oh, it’s ugly! (Laughs).
R: (Laughs).
Galuā: We want it to move, like, ‘cause that’s the only tree on our front lawn, and it’s killing the, you know, the view!
R: (Laughs) Well what is the view behind the tree?
Galuā: Oh, it’s the other houses across the road (giggles) yeah!
R: That tree kinda like really represents a lot aye?
Galuā: Yeah, and that’s the front of my house!

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186 R Samoan Translation: R Tusa lea taofi lea tau puipui fo’i Galuā ona ua ele alu ese male fale?; T E tatau ai ona mafaufau tau ona iai sona mafaufau pe lelei le mea lea pe le lelei aua ilona olaga lea iai, a titiotio la ga ia ilona laitiiti, ae pei ole mea lea ua faofiofi ai na ia ile fale a? Ua le mafai ona alu ile fale olo a ua le mafai ona alu ile mea ‘e fia alu poo lea tava le ituaiga poo se mea.
Ironically, Tulutulu saw it as a beautiful landmark that added beauty to their family home. The tree also offered a welcome shade from the sun and a place to relax with her grandchild.

Tulutulu: This photo is taken in front of the house especially with that tree, really nice, and also it captures our surrounding neighbours.

R: This is a beautiful tree.

Tulutulu: Yes, this is a beautiful tree, at times I get hot so I walk out to the front over there and I sit over there. It's also nice in the summer, go with the baby and sit over there. This tree blossoms.\(^{187}\)

The apple blossom tree was at the front lawn was a regular topic of many conversations between mother and daughter on the front door stoop (Photo 6.26)

\(^{187}\) Samoan Translation: T ia pu’e ata lea ina ia, auā lea oute, foi le manaia ole luma ole fale, ae maise foi le manaia ole la’au ilele, manaia foi auā pei ole e maua uma atu ai nisi au tuaoi laia... Oe ole manaia ia ole la’au lea, e iai le taimi tate vevela ai cta savalivali atu i luma io ota nofonofo ai manaia foi pea oo mai le summer o ma le pepe nofonofo ai lalo i o. E fua ia se la’au lea.
6.6.5 Things we do at home

6.6.5.1 Children at home

Childcare was a regular feature of the day’s events. Another set of similar photos for both mother and daughter are of the smallest and youngest member of the household, 3-year-old niece of Galuā’s and Tulutulu’s granddaughter. (Photos 6.27 and 6.28)

6.6.5.2 Eat, smoke, listen to music all day in the kitchen

Interestingly, Tulutulu made this photograph (Photo 8.29) to highlight one of Galuā’s favourite activities at home: sitting at the kitchen table, writing her songs and listening to music on the radio, and taking care of her three-year-old niece.

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188 Samoan Translation:  R  Tulutulu olea la le va e mafai ai ona alu ai Galuā ile fale e mafai ona pasi ile la’au pe leai?; T Oi ia ele sopo Galuā i luma ole la’au. E gata i luma mai ma le pusua mali. Ao le fale atoa e mafai; R  Lona la ele mafai ona pasi la le la’au lea?; T  Tusa e oo Galuā iluma t; ae le sopo atu iluma i.
6.6.5.3  Share my bedroom with my mum and my niece

An important aspect of home detention for Galuā was her ‘privacy’ and ‘time on her own’.

\[ R \] Which room do you spend the most time in?
[Galua] In this room.
[\( R \)] Oh, in your room?

Photo 6.29 was Galuā’s bedroom which she shared with her mother and niece. of her bed against the wall on the right and her mother’s on the left. Despite the fact, that Galuā’s Housing New Zealand rental had three bedrooms, the family occupied one room for sleeping. At night, they lie at opposite ends talking to one another and awoke at 3am to do prayers. Sharing a space with two other people in close confinement is a stark contrast to the isolation she had on her own in her prison cell on segregated status (Photo 6.30).

6.6.5.4  Need my space, miss the silence of prison

It was this room that Galuā escaped from the most to be alone and to write. Below are the lyrics of a song composition that Galuā read for me during the interview; evidence of a talented and gifted writer.\(^{190}\)

\(^{189}\) Samoa Translation: Tulutulu: Ia ole ata lea ia ole matuai fiapia a o Galuā i le mea lea iai, faalologologo lana la’au, tusa ua iai lona freedom fo lele so se mea e mana’o ai. Ole ‘ai ole utaula aua ole mea a lena e le mafai ona tuua. Pei nao le pau lena.
\(^{190}\) Galuā was reluctant to reveal the identity of the person she wrote the composition about.
Almost made you love me, almost made you cry
Almost made you happy babe, didn’t I didn’t I
You almost had me thinking you were turned around
But everyone knows, almost, doesn’t count
Almost had you saying you were finally free
What was always missing for you baby, you found it in me
You can’t get to heaven, half off the ground
Everyone knows, almost doesn’t count
I can’t keep loving you, one foot outside the door
I hear a funny hesitation of a heart that’s not really sure
Can’t keep on trying, if you’re looking for more
You know I can give you, what you came here for
I’m gonna find me somebody, not afraid to let go
Wanna know, you’d be that kind of man
You came real close
But every time you build me up, you only let me down
But everybody knows, almost doesn’t count
You’ll be sorry, maybe you’ll be cold
Maybe you’ll come running back from the cruel world
Almost convinced me you’re gonna stick around
But everybody knows almost doesn’t count
So maybe I’ll be here, maybe I’ll see you around
That’s the way it goes, almost doesn’t count

Ramona: Do you get silence here [at home]?
Galuā: Um, when the baby’s asleep, yeah, (pause) and when I go into my room, just sit there, lock the door (pause) … it’s different from home when you have a one year old baby running around screaming. You don’t have that in jail (smiles), you have more time to yourself, yeah, and it’s kinda freaky (laughs). (Second Interview)
6.6.5.6 Look at myself in the mirror in the bathroom

Photo 6.31 of the bathroom at home, a space for privacy with minimal disturbance from family members. She was treasured her colourful array of shampoo and lotion bottles stacked on the windowsill. This contrasts with the ‘bare essentials’ of regulation toiletries she was permitted in prison (Photos 6.32 and 6.33), it was another positive aspect of home detention.

Ramona: So tell me more about the silence.
Galuā: And this is my bathroom (giggles), this is my bathroom, I just took the photos ‘cause, its where I spend most of the time looking in the mirror (giggles), and my bed, um, and the kitchen again (giggles). The coming home part, that’s why I kinda like, I missed jail (giggles), ‘cause when you’re isolated, you don’t have anything to worry about, you know, no distractions, you know. But then it says in the bible, you should test your faith and yes, I failed (giggles), ‘cause around other people, you just get distracted and um, when you see something, you just wanna be it and copy it (Home Detention Interview).

6.6.6 Summary

Galuā took photographs of her cell and the letters she made for her co-offender/boyfriend. She asked me for assistance to take a photo of her in her cell.

Most of the photographs taken by Galuā at home while she was on home detention are of family members and friends; her mother helped her to take some of her photos. Galuā produced a photo of the artwork she made from an educational course she attended as fulfilment of her sentencing plan.

As in the home dialysis study, individuals of the same family produced similar photographs, without being aware of what the other was doing. Galuā produced a
similar photograph as her mother of a ‘tree on the front lawn’ at home and their favourite foods.

Tulutulu’s photographs are mostly of herself accompanied by her grand-daughter and close friends at home. She also made one photograph of Galuā’s PID anklet. Galuā was like the pervasive and unrelenting wind, Fa‘asulu and her flight took her into a crime spree, which led her into segregated status in prison. She found quietness and calm by writing songs at her prison desk and watching others outside her window. At home, she longed for time alone to continue her creative writing and found it at the kitchen table, in her bedroom and sometimes in the bathroom.

From her perspective as a sponsor, Tulutulu liked the restrictive aspect of electronic monitoring. Despite the difficulties of confinement, a choice she made to take care of her daughter, allowed her to give constant encouragement to a young person that she lost to the streets. Like the Tailomaloma, she was prepared to endure the pressures of financial hardship as an unemployed single mother and await the completion of her daughter’s home imprisonment.

In the following section, I turn now to the important topic of restorative justice and the participants’ experiences of the Samoan practice of ifoga, a cultural tradition associated with the middle of the house.
Section C - The Middle House for Home Detainees

6.7 The Kneeling House

**Living with home imprisonment – A Family View**

Middle of house

In this section, participants discuss the relevance and importance of five Samoan cultural traditions at the middle of the house. *Ifoga* is a formal apology practiced by Samoans for the redress of wrongdoing. It is recognised as a restorative justice intervention within the New Zealand judicial system. Figure 6.4 (above) highlights forgiveness (*fa'amagalo*) as an important option and obligation in Samoan society, and its relevance for detainees and sponsors. Senior family leaders that can help to resolve issues between family members can begin with the restorative practices at the middle of the house, as described in the stories in this section. Other important characteristics associated with healing and redress, can be supported and reinforced through other interventions such as the observance of religious prayers, Samoan tattooing, and visits to family graves.

6.7.1 ‘NZ born’ and the lack of fa’aaloalo, respect and remorse

The level of ‘shame’, ‘humility’ and ‘remorse’ that a prisoner exhibits in relation to their crime can reveal a detainee’s capacity to cope with imprisonment and their
capacity to reoffend. Maota’s responsibilities as a Receiving Officer (RO),\(^{191}\) was to interview and assign prisoners to a wing and cell (room) in accordance with their formal classification and status.\(^{192}\) Whenever he asked Samoan prisoners about what they missed most; they often responded that it was loss and separation from their families on the outside.

\textit{Maota:} …\textit{that’s about the time that you see tears in the eyes…}

Over two decades Maota observed that Samoan prisoners, more than “other races”, were prone to express feelings of shame for their crimes.

\textit{Maota:} I’m not sure whether its culture at all, I feel that, they’re not just shamed for themselves, they’re ashamed for their families. They’re ashamed for their mums and dads, and family connections…it’s ah, the feeling you’ve let the family down, you’ve let mum and dad down.

Being “ashamed” motivated some Samoan prisoners to use their less known legal identities, or change their names. Maota believed that it was a way to distance the stigma attached to their crime.

\textit{Maota:} Some they really wanna talk about it, and you can sense it that they are ashamed, a lot of them also come in and use their maiden name, rather than their other name…I mean, if that plays a part in stopping them from reoffending, then why not, yeah, why not if it helps out, while they’re out in home d, why not?

Key informant Tao witnessed an Ifoga ceremony in Wellington when he was a young boy, between families who knew each other well.

\textit{Tao:} Wellington where I grew up, if your son hurt another son, like …when a boy from your family beats up another boy and nearly killed him, and, so, I know of a family where they went to this family with the son, and knelt on the front yard, and just stayed there until the head of their family said, “Look, you know, and, he gave them that, um, that reassurance that everything’s been set right, you know.

In a high profile incest case involving three young minors, the offenders’ families apologised by Ifoga to the victim’s family. As a sign of goodwill, the family of the victim accepted the apology and then “strongly opposed” the verdict of imprisonment at court that was made against the two offenders. Because of the serious nature of the offences, the offending youth were sentenced to youth prison. The case

\(^{191}\) Maota was RO for nearly a decade at the prison.

\(^{192}\) Detainees are classified as: Segregated status; IDU: identified drug user; low, medium or high security risk.
highlights the willingness of families to work together to find some common ground on a very serious criminal incident.

**Upu:** Because she (victim) was only 14….Inevitably they were [imprisoned], because the crime was so great….But, the victim’s family turned around and strongly advocated, that because the Ilfoga had been done, and for the judge to send these boys to prison, was almost like, an affront of the cultural processes that had taken place.

The differences between those raised in the “Island” (Samoa) and those raised in Aotearoa/New Zealand can often be very marked.

**Maota:** I think that the Samoan born are more respectful…I’m not sure whether they’re more remorseful, but they’re certainly more respectful than the NZ born that come through. I don’t know why, have no idea, probably their upbringing.

**R:** They identify quite strongly with their values?

**Maota:** About being Samoan, yeah.

Other observable differences include the way that detainees demonstrate self-care and “appreciation” of what they can do given their circumstances in prison.

**Unu:** …the way she [Lisi, Island born] cleans her room, you know has her shoes outside… and um you know things like her plastic bag, she folds her plastic bags and saves her, you know whatever she can do, her hair ties and her food. She never minds what she’s getting, even though she gets the same five days menus, five days a week. Whereas [Ane, New Zealand born] the other one’s happy to just leave it there for the sun to get at it, or the flies to get at it, and then come and moan about this and that and pick off other people’s food, and there’s a different appreciation in both of them.

Ane’s ambitious behaviour to impress and be noticed by the “Queen Bee” identified her clearly as a “blender” within the prisoner hierarchy. This behaviour was typical of the bravado that young New Zealand-born Samoan offenders displayed.

**Unu:** When Ane comes over to her and tries to stand over Lisi, Lisi’s quick to say, “No!” And you know puts her guards up and she’s quite prepared to have a fight if there’s gonna be one there. She’s [Ane] a blender, she’ll do whatever to keep the Queen Bee happy! Even if it means, you know going to hurt her own kind… ‘cause it’s totally different for them being prisoners.

Disrespect and lack of remorse was a consistent pattern that was observed within the courts system as well.
Upu: There’s a complete lack of respect there from NZ-born kids, that…just doesn’t feature with Samoan-born kids, you know, they understand the concept of ‘fa’aaloalo’ (respect) and there’s a limit. Even though the crime might be horrendous, the remorse comes through. Now with some of the NZ-born kids, you know, just the sheer bloody minded rudeness! It’s almost incomprehensible! And I can’t believe that those families that those kids come from, raised them like that, that can’t be right!

One of the main goals of home detention is that the detainee makes the best of the opportunity to live their lives without reoffending.

Pu’e: ‘Cause it’s important for them to know what they’ve got and…what they haven’t got; and now that they’ve got it you know, look after it, use it well…Yeah, for some…prisoners it’s a real turn around. It makes them really regret a lot of things and think about, “Well next time I won’t do this!”

When considering the causes behind offending patterns, Pacific youth can be more prone to seek advice and guidance from their peers, rather than from their families. Tao observed that many who are “alienated” from their families seek support and social status from urban gangs and anti-social networks. Families become involved with the youth when it is too late.

Tao: I’m picking that their home links are gonna be next to nil; ‘cause, that’s why they left home. That’s why they were on the streets, because the home life wasn’t the ideal picture, that they pictured it as. So they got their strength from their peers. And, I mean, being on the street, no money, no nothing, so that led to the crime wave that they were on and I think it was a case of you know, it’s easy to do if you get away with it. Then you do it again, and then they only see the seriousness once they come to us.

Samoan families’ incapacity to transfer cultural values and practices from one generation to the next can also potentially impact upon an offender’s significant lack of remorse.

Upu: I think it comes down to the poor transportation of cultural values between generations, I think it comes down to lack of effective communication skills between parents, I think it’s um, I think it’s the issues in the home that can be dealt with, you can’t be out saving the world and yet your own backyard’s falling apart, you know, but, but often our parents that um, that migrated here, you know in the 30s, 40s, 50s, sometimes they’re still locked in that mentality, and what they forget it’s important to tell your children why, you hold certain values, why you do things a certain way, yeah, that’s how it see it.
The reason Pacific people have high rates of fraud and violent assault is unclear even the most experienced prison officers. For first offenders, like Galuā and Foe, with no previous history of offending, it is also difficult to explain.

*Maota:* *That girl Galuā, she’s got no history, she’s got absolutely no history of crime, aye, and then suddenly, gets out there and beats somebody and you know ohhh (sighs)...The majority of them if they’re not in for fraud...property...and if not then it’s mainly a violent offence. I don’t know why, I haven’t figured out why.*

The influences of American music celebrities like ‘Tupac’ and other hip-hop-gangster rap musicians often promote images associated with illegal wealth, violence and idolised status. These images can be seen within the prison environment and emulated in a detainee’s values.

*Pu'e:* *Their [Samoan born prisoners] pictures [posters] are different, totally different from some of the pictures that you see in perhaps Mauli [prisoners cells], no disrespect to the other ethnic...Well, they've got the likes of um, Tupak, and all those rappers, and ah, what's those that American sort of um gangsters...*

### 6.7.2 Forgiveness as a construct of the built environment

Humility and shame are the human virtues and cultural values which Samoans consider critical to the maintenance and restoration of social relationships, behaviours and social responsibilities. As discussed in Chapter Three Samoan society is determined by the inter-dependent connections that people have with their outdoor environments *va tapuia*. Thoughtless acts of violence and aggression are not acceptable and are under the control of those mandated to protect peace and social order, such as the armed forces, police and village guardians. Individuals and families are themselves encouraged to emulate control and restraint particularly under difficult circumstances. *Ifoga* is an important traditional process that emphasises the observance and promotion of ‘forgiveness’ between families when relationships are ruptured by acts of violence and other serious wrongdoing. In Chapter 3 Epistemology, the virtues and qualities of bravery and courage are symbolised by the armoury and weaponry used by Samoan ancestral heroes and warriors, which, is part of the continuum of the Samoan life journey (right side of the house) and Samoan cultural wealth (left side of the house). I suggest Sponsors and Detainees have separated roles and responsibilities (as set out below).
*Ifo*ga is underpinned by the concepts of peace, forgiveness and humility; and is formally recognised as a restorative justice intervention by the New Zealand courts as part of proceedings, wherever it is deemed appropriate between the plaintiff and defendant parties (227). Figure 6.4 above shows *Ifo*ga is associated with the act of human forgiveness and humility and that this is symbolised by a fine mat *le fa’amagalo* (*mat for forgiveness*). When wrongdoing occurs, the rupture in human relationships needs to be restored and this is done in a formal ceremony involving the offender kneeling in front of the aggrieved victim covered with an *ie fa’amagalo* (*mat of forgiveness*).

The most important and critical aspect of an *Ifo*ga is ‘timing’. The aggrieved as well as the offending parties should have sufficient time and space to be consoled before taking any decisive action. Metaphorically, an apology is best made when the “tree branch is not too green” and is “dry” enough to ensure that it “breaks cleanly” rather than fracturing to pieces (*gau mata*) (228).

### 6.7.3 *Ifo*ga as restorative justice underneath the mat

On the day of her *Ifo*ga, Galuā remembered her family being very upset when the officials confirmed that the victim would not be attending the court proceedings. The family saw the victim’s absence as a clear signal of not being ready for an apology.

**Galuā:** The *i*fo*ga*, oh, yeah. I’ve never heard of it before…they were telling me that, we had to cover ourselves in the fine mat…and that the victim would take it off me, whenever she wants, if she’ll forgive me or not… And then oh, the day came for that to happen, but the victim wasn’t there. We were kinda gutted, but, you know, can’t blame her, but yeah, it was, it, it just felt sad.

Against their better judgement, the family continued with the ceremonial apology, hoping to gain the empathy of the presiding judge not to send Galuā to prison. However, it was a decision that they later regretted, because when Galuā was sentenced to jail, the apology was seen as lacking agency.

**Tulutulu:** It would have been better that the woman had been there; if we had known when we were coming together to organise the *Ifo*ga that she wasn’t coming, there would have been no *Ifo*ga, aye?\(^{193}\)

\(^{193}\) Samoan Translation : \( R \) If you know that faapea la na outou toe iioa e le sau le victim, would you have still, e fai pea a le e tapena pea la faiga ole *Ifo*ga pe leai?; \( T \) Sa sili aua leaga faapea e alu atu le faino e e iioa matou e alu atu fai le *Ifo*ga ae a faapea le alu atu e leai se *i*fo*ga* a?
In light of this, the family asked a third party (the New Zealand Police) to convey their apology to the victim and to present their mat of forgiveness as a sentiment of Galuā’s remorse. However, a few months later the victim refused to take the mat, which the police then took back to the family. The family’s second attempt to apologise to the victim left them again feeling disappointed and somewhat unresolved.

*R:* So did you think it was a waste of time then doing the ifoga?
*Tulutulu:* My guess is that no one took any responsibility to acknowledge what we did. To us we know it was a waste of time but it really hurt us, because it was the fa’aSamoa. The worst thing is the fact that Galuā went to jail. No one had discussed or explained at the time what was likely to happen. My brother spoke in English and translated the meaning of the Ifoga. But the whole time, to me it seemed they didn’t even care. Andrew [Youth Aid Officer] who represented the victim, my brother told him that this [ie toga/fine mat of forgiveness] was to be given directly to the victim, the toga [mat] had covered the both of us [me and Galuā] and was offered as an apology for the wrongdoing, for the offense that Galuā committed, aye? But no, Andrew [New Zealand Police] just held onto it.\(^{194}\)

Ifoga is a process where the offender’s family are willing to publicly take responsibility and apologise to the victim for the wrongdoing that was committed. An Ifoga can generate a high order of consultation between chiefs (matai) and family members because of the serious implications surrounding the wrongdoing.

*R:* How did you feel that your uncles actually came, and your Aunty?
*Galuā:* I felt loved (giggles), yeah, I felt, like, yeah, there was heaps of support, um, I had heaps of support. ‘Cause, it’s, like, when you’re under that fine mat, you’re full of shame and embarrassed of what you did, yeah, and you’re covered ‘cause, I think you’ve done that to your family. When you’re under that fine mat, it’s more noticeable than being on home d. um, yeah. (Second Interview)

The apology Ifoga can create strong emotional responses for the individuals involved.

*Galuā:* But with my Mum there, it kinda made me have to do it, in, a kinda way…um yeah, like, (pause) I can’t explain it, it’s like, when you’re

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\(^{194}\) Ia oute matea leaga leai ma seiši o latou o faapea, eleai seiši o latou they do care poo except ina le mea lea na fai e matou. Iloa matou ua waste le time ae le’e, but ole mea pei, the other thing e tigā ai le fato o matou matauila that’s a fa’aSamoan ole mea sili atu lea na fai e matou ae lea na end a alu Galuā le jail. E leai foi seiši o latou faapea na tautala foi ilele e explain lea latou ia aua lea na tautala olou tuangan lea na tautala ile eglisi ma faamatala atu e ia ia latou le uiga ole mea lea Ifoga, a ole mea e faapea ma faapea, e leai, mea na na Iloa ai e au ele kea. Tusa lea avatu, tusa o Andrew [Youth Aid Officer], na o e represent le victim. Tusa ia na fai atu Iloa Iou brother ole mea lea e ave sao a io ma fa’amatala le victim. Tusa ole lea na pulou ai maua ole is na e faamagalo ai agasala, le mea seisa ua fai e Galuā a? Ia ae leai, lea na tuu tuu a io e Andrew [Youth Aid Officer].
kneeling and covered over the fine mats (pause, pensive). We were crying, but the youth advocate that was there Andrew,\(^{195}\) he took it off. Um, my lawyer was even crying, yeah.

Two years had already passed since apologising at court, but the experience still resonated deeply for Galuā and her mother.

\(R:\) What was it like to be kneeling under there with your mum?

\(Galuā:\) Angry and sad, shocked, yeah (pause). ‘Cause, no one in my family, would you know, expect me to do that kind of thing (crime).

As was the practice of the Samoan families in the dialysis study, Galuā’s family carried out a vigil of daily prayers during her term of institutional imprisonment, a practice that they continued through the duration of her home detention. Prayer helped Tulutulu in particular to cope with the disappointing outcome in relation to the Ifoga.

\(R:\) Tulutulu how do you feel about the fact that the victim still hasn’t seen you? Or do you feel like it’s finished, do you still feel you need to go to get her forgiveness or anything like that?

\(Tulutulu:\) Leai. No.

\(R:\) Why?

\(Tulutulu:\) Because of Novena,\(^{196}\) we began at three o’clock in the early morning, prayers offered for the woman (Victim) and Galuā. Right up the time when Galuā went into prison, we kept on praying. We prayed three o’clock in the morning, do our Novena, asking for forgiveness and offer prayers. Right from when Galuā came home we’re still doing Novena. We pray, we pray for the woman that was affected by what Galuā did.\(^{197}\)

Given the significance of the ifoga for the family, I asked Galuā why at the prison interview, she had not mentioned it.

\(R:\) You didn’t mention that Ifoga?

\(Galuā:\) ‘Cause (pause), um, doesn’t know, never really thought of them (family) in there, yeah… I didn’t want you know, to have anything to do with family when I was in jail. You can’t really think of them when you’re locked up (giggles). You kinda like think of yourself, only, it’s kinda selfish, but yeah (pause)…

Perhaps embarrassment and shame stopped Galuā telling me about the ifoga. If so, then this as well as the written apology she tried to make to her father were acts of

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\(^{195}\) Andrew: pseudonym for the NZ Police Youth Advocate who attended.

\(^{196}\) Novena – a Catholic practice of early morning prayers.

\(^{197}\) Tusa o novena na e amata le tolo ile vaveao e momoli mo le fafine ma Galuā. Oo a ile taimi na atu ai Galuā i totonu fai a le mea lea a matou, we pray three o’clock in the morning fai le matou novena. Oo foi na sau Galuā i tua we still doing the novena. E tatalo matou e tuu atu e talosia ai le fafine lea na tupu ai le mea.
contrition which are consistent with the changes expected of someone following an Ifoga.

Galuā: I still don’t wanna do things or face the – shameful! I do feel that - being a Samoa. I do feel the shame and, and my dad now, he doesn’t want me anymore, ‘Cause of, ‘cause I take his last name and in the paper, he doesn’t wanna know me anymore.

R: Did he tell you that?
Galuā: He told my sister and my sister told me.
R: How did that make you feel?
Galuā: Stink.
R: Why?
Galuā: ‘Cause inside, I thought like, no matter how (poised and tearful) much a daughter could be that is his daughter (begins to cry).

R: (Softer) Have you had any contact with your Dad since you’ve been in prison?
Galuā: Nah.
R: Want to talk, make contact yourself? Have you written to him or anything?
Galuā: Nah (almost whispering, crying, sighs). My letter’s in the bin.

In spite of the significant experience she shared with her mother by kneeling in humility at court, Galuā still seemed unable to accept that her mother completely disapproved of the relationships she wanted to continue with her co-offender. Sadly, she saw her mother as a potential barrier to home detention.

R: What would help you to stay in your home detention? How many months will you have to do it? How many months are you on?
Galuā: Nine months. ‘Cause if I put my head on, focus on it.
R: What are some of your weaknesses?
Galuā: (laughs) My Mum. (Prison)

Galuā’s anger towards her mother had completely changed by the time we met again for the home detention interview, which was a few months later. Being home, the two had rebuilt a new relationship, with Galuā acknowledging the ifoga had helped her to settle back home again.

Galuā: Coming out on home d. Like if I didn’t do the ifoga, I still would’ve had a bit of guilt and you know would’ve felt, oh, you know, “Now everyone’s gonna see me… (Giggles).” They’re gonna be like, “Oh look at that girl!” Yeah, but I’ve, did the ifoga, and now I’m like come out, doesn’t matter what anyone said, I already been under the fine mat and yeah. (Home detention)
The *Ifoga* allows the offender to experience “reintegrative shaming”, where disapproval occurs within a continuum of respect.\(^{198}\) This seems to have been an important outcome for Galuā on home detention, despite having broken the conditions of her sentence in a recent incident.

*R*: Do you think that having done the *ifoga* has it helped you do your home detention?

Galuā: Um, yep, oh sort of, oh, like ‘cause, that was like letting all the shame out, you know, letting everyone know how sorry you are. So when you come on home detention it’s just like, it’s kinda like, oh, you’ve done all the, you know, the saying sorry. So you can just come out and just move on (giggles). You know, try not to do anymore breaching or, yeah, just follow the conditions, yeah, quite easier. It is quite easier when you’ve done the *ifoga*.

After she breached her conditions and faced with the prospect of going back to prison, she remembered why her family had gone through with the *Ifoga* and hoped that the positive changes in her life would be long-lasting.

Galuā: …Yeah but when you’re out here on home detention and you’re surrounded by people who stay with you, my mum, always reminds me of her brother… like my Aunty, her cousin (giggles) and um, like, when she’s talking to other people, or like you know, giving advice. She reminds me my uncle, my brother, and you know it just brings the whole thing together (giggles).

One of the key advantages of the Samoan built environment at the ‘front of house’ is that elders within the family understand that they have a role to assist in serious matters such as restorative justice and mediating family disagreements. In the next section, Foe talks about how she was challenged by her mother to ‘forgive’ someone in her family, learning that ‘forgiveness’ is an important virtue and responsibility of the *Ifoga* process and restorative justice framework.

### 6.7.4 Mother’s advice to forgive another family member

During her term on home detention, Foe and her mother had an in-depth discussion about an *Ifoga* carried out between two local Samoan families involved in a murder case.\(^ {199}\) The offender’s family had made three separate attempts to apologise and it took more than a week for the victim’s family to accept the apology.

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\(^{198}\) Cited in Tuala, based on the work of John Braithwaite.

\(^{199}\) The case was well covered in the media and involved Susana Brown, a Samoan woman that was murdered by her ex-partner at Titahi Bay beach, near Wellington.
Foe: I reckon it’s really good, you know, just to bring peace between the families...like I knew people who...went and supported, the young [woman’s family], um, that ... when the family [offender’s family] came to them; she [victim’s mother] wasn’t too, you know, she didn’t want to accept... she didn’t accept it the first time. But I think the second time, and maybe the third time they came back, you know, and she said “It was a hard thing to accept”.

As their discussion developed, Foe knew that her mother was trying to encourage her to see the Ifoga as an important cultural process of forgiveness. She could understand her mother’s concerns about allowing anger to consume her and cause deep emotional and spiritual problems.

Foe: She [Foe’s mother] was you know, going on about the ol’ forgiveness, you know, “If you don’t forgive it’s just gonna, just, chips - just gonna, always just eat you up, you know (pause)! No use holding the ol’...” But...like I was thinking, “I understand that he just killed, you know, murdered their, their daughter!” And she goes, “Yeah, but, she [victim's mother], she’s the one that's holding the grudge, it’s hurting her not him [perpetrator],” you know, “all, all that hate, and that’s just”, you know, “just boiling up and eating her up inside”.

After Foe took up her mother’s advice to make peace with her cousin, she was left feeling more frustrated.

Foe: But I tried to talk it out with her [cousin], but it’s like you know...not being honest, and I said, “How can you fix something with someone who’s just gonna lie? And she says [mother], “Oh, you know just let it go!”... ‘cause she [mother] could see that it was just eating me up, “See, she’s... getting the better of you!”

Despite this, Foe could not deny her mother’s well-intentioned advice; it made her think seriously about the potentially negative consequences of not to making positive changes in her life.

Foe: She goes, “You’re angry with your cousin and you’re holding this grudge! Your cousin’s alright...she’s not being angry, and look you’re being hurt and all upset over something that she’s done!” You know, “Just think about it!” And I was like, “Oh, oh, yeah, (quiet voice)”, Suppose, you just, you just have to let it go (sarcastically). Is like, oh, ‘Is gone!’ (Laughing)

Her mother was not the only one involved in providing advice and guidance during home detention. Going home, Foe knew there would be some major adjustments of living at home again. It was the first time for her to live with her siblings and her mother since her grandparents took her away at the age of six. Her younger siblings
cautioned her by saying that since moving in she was “rocking the boat a bit too much”.

Foe: I’m going, “Well you used to talk to us like that!” Like with me, I grew up with my grandparents, they’re quite mellow and you know, I didn’t like the yelling and screaming and that, you know, it’s like “Gaww!

When conflict arose between Foe and an older sibling, her mother asked an elderly Aunt from within the extended family to help mediate some long-standing issues between them so that peace could be restored again.

Foe: Yeah, well, like that’s my mum’s older sister. She’s always, you know, like since we’ve been growing up, she’s always been our mediator…I was upsetting her (sister) with the things that I was doing...that’s when my Aunty just said, “…You don’t say it… in front of her [niece], ‘cause…you’re belittling your sister in front of her!”

In the next section, I present some of the views that key participants shared with me about the importance of shame and humility in the rehabilitation of offenders and other accounts about Samoan families’ experiences of Ifoga as restorative justice.

6.7.5 Tatau/tatoo

In prison Foe talked about how her tattoo (Photo 6.34 and 6.35) which was an important aspect to her Samoan identity. The tattoo had been done by the son of master tattooist Paulo Suluape when she was 16 years old, at the family home nearly twenty years ago. The cultural wealth associated at the middle of the Samoan traditional house is linked to the Ato Au Basket of Tatooing Instruments (refer Figure 6.4 shown earlier).

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200 I had helped Foe to take the photograph of her wrist tattoo on the day that I visited to collect her film to be developed.
201 Paulo Suluape (of the Sā Su’a family) was a renown Samoan tattooist who helped to revive and encourage tattooing through collaborative exhibition forums and festivals in Aotearoa/New Zealand, the Pacific region and the United Kingdom, Asia and the United States. Public scandal surrounded his death when he was killed by his wife at their Auckland family home in 2001.
Foe: You know my sister, and a few us, a few of my cousins and that, all, got our taulimas (arm/wrist bands) and my cousins got their tauvaes (anklets) done... I think it would've been 8, 10, oh, even 10 of us I think it was... I said, “Oh can I have it in the middle?”; and he goes, “Oh, well, nah! You gotta get it round your wrist or up, or your ankle, unless you wanna get a malu [full female body tattoo] done”, I said, “Oh, no, no, no!”

Inside prison, her tattoo (taulima) bracelet served as ‘proof of identity’ to other prisoners that she was of ‘Samoan’ descent; she was often mistaken as Maori or Pakeha.

Foe: Oh, “You don’t look a Sa, are you Samoan? You look like you know, oh you look like a Pakeha, you look a Maori” I said, “I don’t know what’s more insulting!” (Laughing). ...But, then most times if I’m wearing a tee-shirt or if I’m wearing a jumper, they wouldn’t know.

R: So your taulima gives it away?
Foe: Yep, yeah, pretty much (laughs).

She was curious about the significance of the full-bodied male tatau (pe’a) and the female tatau (malu) that her Uncle and Aunt had done on the day that she herself was tattooed.
Foe: Get a bit sick of it, oh, I wouldn’t say I am if I wasn’t you know… doesn’t really bother me you know if they don’t believe me (pause). Yeah, nah wouldn’t mind finding, yeah, finding more about it. (First Interview)

As it was shown in the dialysis study, participants value the unique tradition of *tatau* and the importance to one’s social identity.

### 6.7.6 Family graves

Death is an inevitable aspect of life and family graves are considered as a normal extension of the family environment. Amongst her photographs are pictures of family graves that she often visited during home detention. The cemetery was one of the first places that Foe said she wanted to go to after release from prison.

![Photo 6.36 Foe’s grandparent’s grave (back view)](image)

Foe: Oh, yeah, I’ve been, yeah I’ve been up there a few times since I’ve been on home d. It’s a good place to go and, you know, like visit, and, bit, like a bit you know, closer to them, even though that they’re gone, but, yeah.

R: So they’re there and there are some other family around them too? (Looking at photo) Back of the headstone… do you wanna read what that says?

Foe: Um, “Fondest love from your grandchildren and your great grandchildren."

Foe’s close bond with her maternal grandparents from the age of six was important and when they died it deeply affected her; she credits them for instilling an appreciation and acceptance of her Samoan culture. Seven photographs in her

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202 On the day when the photographs were taken, Foe was granted permission by her probation officer to go to Sunday Church and then to the cemetery; however after a night of partying she slept in. Instead, she asked her sister and her mother to take her disposable camera and take pictures at the grave site for her.
photo album for the study, which her family helped to take for her, are the graves of her maternal grandparents and other close family members.

![Photo 6.37 Grandparents grave (front)](image)

**Foe:** Yeah, after my Grandma had passed away (pause), where with my Mum, my Grandmother was my mum. With my Mum, she was just, she was just, my mum (laughs) oh, you know (pause) she was just the lady that gave birth to me… I miss her heaps.

**R:** You think about her while you’re in here?

**Foe:** Yeah, yeah, yeah, yeah, I think about her here, quite a bit. (Prison)

![Photo 6.38 Family members at grave site](image)

### 6.7.7 Summary

*Ifoga* helps families to come to terms with traumatic events caused by serious wrongdoing. It also provides an integrative process for families to restore balance and healing between relevant parties affected by the detainee’s wrongdoing.

An important component of *ifoga* is the consultative advice of family leaders who as in Foe and Galuā’s cases facilitated the formalities involved with ifoga and helped as mediators between relevant parties. Galuā offered a formal apology to the victim of her crime in the form of an *ifoga* at the Family Court. However, the family said that it
lacked agency because of the victim’s absence from the proceedings and because it did not prevent Galuā from being imprisoned. In terms of its effect on both Galuā and her mother, ifoga provided an on-going and effectiveness cultural framework of instruction about the principles and values of humility, shame and justice. Under the circumstances of being segregated from other prisoners, Galuā was able to find support from older prisoners who encouraged her resolve issues at home.

Key informants provided insights about the increasing changes amongst offenders entering the courts and prison systems. New Zealand-born offenders consistently demonstrate more disrespect and lack of remorsefulness in relation to their crimes.

The participants acknowledged the importance that prayer, tattoo, and family graves make to one’s identity as a Samoan person and that these are held to be important by their families.

Section D Major Challenges of Home Detention - A Difficult Sentence

6.8 Introduction

Home detention can give the false impression that it is an ‘easy’ sentence. As highlighted in the last section, key informants use factors such as remorse, shame and humility as indicators of a detainee’s capacity for change. Unu was interested to see the extent that the detainees in the study experienced their homes as places that reminded them of the prison institute and what factors had a ‘deterrent’ affect that could motivate them towards successful completion of their home detention sentence.

Unu: It’s because um, it’s not like prison, you know you’re in your home environment, you get to sleep in a bed that’s not like, the hard ones in prison…you get to, I mean the smell around the home is different …the atmosphere at home is different.

R: Are you interested to see how much they notice that? Whether that comes up in what they share about their home?

Unu: Yeah, and not just come out, “Wow I’m free, I’m gonna do a,b,c, d, but I’m free and I’m so grateful that I am.” You know, just being really grateful!
6.8.1 Urban Youth Gangs

In prison, gang association and membership is ‘currency’ for status, allies and immunity from foes. Gang membership appears to be higher amongst the Maori prisoner population at 21% (of 866 surveyed) and 5% for European (147). Prison officers in the study observed that young Pacific offenders appeared more likely to belong to a gang than older offenders but that overall the rates of membership was fairly low.

Urban street gangs in big cities offer attractive social opportunities to youth seeking excitement and risk. Young offenders can become particularly vulnerable to factors such as isolation and depression, if they are unsupported by their families.

Tao: When you’re by yourself, you feel alienated and then, you start to feel depressed, and there’s no-one to draw on. Whereas, the generation next to ours, of the ones that are growing up now, find that, yeah, with their culture, seem more to identify with their peers, not so much with their families.

In my first interview with Foe, she wanted to make it clear that she had no gang affiliation in prison. One of the reasons she left Wellington almost a decade ago was to distance herself from some friends that had close links to the Mongrel Mob and Black Power gangs. It was getting more difficult for them and for her to escape the drug and criminal lifestyle that functioned within the gangs.

Foe: Nah, into that buzz…I’m pretty neutral, I’ve…got my own two feet, I don’t need no colours…over there Aussie I’ve got you know a few Bikie mates, it’s really up to them what they wanna do, that’s their buzz, but you know, I’m not a follower (pause)…I’m just into…myself and my family, more or less just working, and just saving…just trying to help my Mum out with my younger sisters…and come back and you know see my Nan (grave at the cemetery). (First Interview)

She noticed that when she shifted into a wing where there was less hostility, there were fewer gang-affiliated prisoners.

Foe: After that went to ( ) Wing, and, nah, it was pretty, yeah, the women there are a lot more mature and not really into their ‘gang-bangers’ (emphasising) or that bull-crap! Yeah, but, nah, after that was pretty sweet (First interview)
On home detention, Galuā produced two photographs about her gang involvement before she was imprisoned and how she had never considered the consequences of her crime (Photo 6.39 and 6.40).

![Photo 6.39](image1) Galuā and how she used to be in the streets

![Photo 6.40](image2) Galuā’s cousin re-enacting the beginning of her troubles in the gang

Galuā: Yeah, and I took this one of the bandana, ‘cause this is what I used to be and what I used to do. I used to walk around the street wearing that when I was in Auckland (pause) and yeah, that reminds me of jail. ‘Cause in jail there’s heaps you know they don’t, the correctional officers don’t [know], but when you talk to the girls, they’re in this gang and that. That’s my cousin, my Aunt’s son, he just wanted a photo (giggles). (Home detention)

Prison officers said that they can usually determine prisoners with gang affiliations and those who try to claim status by association only.

Unu: Mongrel Mob, it’s just really friends of friends of friends, but yeah!
R: No direct [involvement]...she wasn’t really a patch member?
Unu: Oh, she tries to make it like she is, yeah! (Laughs) “Yeah watch out, I know her! I know him!”

6.8.2 Alcohol, addictions & unresolved grief

In consideration of the fact that 89% of New Zealand prisoners had substance abuse and dependence issues (6), many prisoners rarely get the required help they need inside prison or by the time they are released into the community. Helping detainees to resolve their drug and alcohol issues was still viewed by Unu as an important role of the Prison Service.

Unu: [Prisoners] have unwise choices and maybe, you know, from my life experience I can relate to some of what they’re going through, being brought up in a home that was dysfunctional and having a father that
was an alcoholic, you know, and even raising children on my own, being a single mum, working in a prison, you know I can relate to women.

Drinking had been a major influence in Foe’s conviction and she was ordered by the courts to get help. Foe had been drinking heavily prior to her conviction when she attended three separate funerals over a period of four to six weeks; attending the funerals was the main reason she travelled back to Wellington.203

Foe: They said I’ll have to do my, um, like AA and One-to-One counselling. ‘Cause, I was drunk when I offended…I don’t really drink that much anyway, but that’s what they said I have to do, so I done that, and a anger management course…I pleaded guilty to assaulting the girlfriend but not guilty to assaulting the guys…I had my JDs (Jack Daniels Whisky) 40 Oz bottle.

As part of her sentencing plan, Foe was required to do anger management and drug and alcohol counselling. Her family helped her to find an alcohol counsellor, and within the first two months on home detention, she completed individual counselling. To continue her progress, Foe was keen to start anger management counselling before she became distracted by her former social networks, some of whom were active drug users.

Trying to get assistance from her probation officer was difficult, because Foe was told that because she was a ‘first offender’ under the ‘66% Rule’ and “not high risk”, she was ineligible for the Corrections criminogenic courses in her local area.

Foe: My probation officer…asked me about that anger management and she kept on, like “Oh, well you can’t do that, oh, you don’t fit into that category, oh, you don’t fit into this category, you can’t do that”…she just kept on, like more or less didn’t give me any help. Like what I did ask her for was just that one programme…

One of Foe’s friends was still heavily involved in the drug circles with the gangs and had been put on notification by Child Family and Youth Services for the neglect of her children. Foe was extremely disturbed that the children were being “dragged to the ‘ol ‘P’ (methamphetamine) House”. Being back home only reinforced her view that Wellington was and continued to be a very “depressing place” and that she needed to ensure that her home detention was completed, without any breaches to the conditions of her sentence.

203 Foe attended the funerals of two cousins aged late 20s and mid 30s, one who died of cancer and the other of suicide. The third funeral was of a friend who died of drug overdose.
**Foe:** [Friend]’s partner wanted me to take back their eldest girl, she’s eight. ‘Cause she’s just hooked on that ‘P’ too, she never used to be on it, it wasn’t until, yeah, he passed away. She’s more or less lost everything that they had…everyone just turned their backs on her. ‘Cause I just said to them, “It’s just a sickness that she’s got, it’s not her, it’s just you know the addiction has just gotten to her”.

It took five months for Foe to finally find an anger management counsellor, which again she did on her own with help from her family.

**Foe:** She (Probation Officer) goes, “You’ll have heaps of time”, and I said, “No, I wanna, get it (counselling) all done with now”, that was part of my, you know, release conditions…I told her about two weeks ago, I said, “Oh, well have you spoken to (Counsellor)?” and she goes, “Oh, I haven’t really had time”.

### 6.8.3 Boredom

Boredom was a constant problem of the institutional environment but when she was released to home detention ‘boredom’ had been something she had not expected.

**R:** Your room compared to your cell, do you wanna talk about that?
**Foe:** Yep, oh, there’s not much um, oh, there’s no lock on the door (laughs)... um didn’t really think on how, you know, how boring it was gonna be...Just, like, oh, I just thought, oh you know, just being at home and not, you know and not being in there [prison]. You know, having to, you know watch what I do and watch what I say, you know and being told, you know, what to do, when to do it, how to do it (grinning).

### 6.8.4 Stigma

Home detention can stigmatise a detainee and impact their capacity to integrate successfully back into society. When Foe tried to join a local sports team, she was met with huge disapproval, because some of the players had connections with the victims she assaulted. She felt incredibly discouraged and left the team.

**Foe:** ‘Cause it just always comes, you know hits me back in the face, and it’s always, “Oh...that fella’s, oh that bloke, his cousin was in the team”, you know and “her mates and they’re you know...”; and then join another team and its...if I go out, I just get reminded of it all the time....I just said to my mate, oh, nah, can’t be bothered

At the time of registering for home detention, prison officers try to impress on detainees that going back home might not be a viable option, if the pressure of resettlement is too risky and likely to lead to reoffending.
‘Cause it’s important for them to know what they’ve got and...what they haven’t got; and now that they’ve got it you know, look after it, use it well...Yeah, for some...prisoners it’s a real turn around. It makes them really regret a lot of things and think about, “Well next time I won’t do this!”

6.8.5 Education programmes in the community

Foe left school at the age of 14 and lived overseas for nearly a decade and said that she needed to talk to someone about the available options of retraining and employment. She asked her probation officer about doing a polytechnic course and was told logistically it would be too difficult and too costly to install surveillance equipment at a campus location. For courses she was told to look in the “yellow pages”; a suggestion that made her feel like she had been “thrown into the deep end”. Given the length of delay she experienced from her probation officer, Foe said that she could have easily finished a “basic” computer correspondence course at home.

Foe: I say, “Is there a course that I could that’s just in one classroom, and, where Chubb could monitor me (laughs)? You know it just put you off!...I don’t know; the not knowing.

Despite a two-month wait, Galuā was supported by Corrections to complete a three-week life skills course with a private Māori training provider and said that she thoroughly enjoyed herself. She produced a photograph of an art work that took her three days to make on the course. The design reflects the importance of her Samoan cultural identity as well as the principles of Maori tikanga (protocols). Displayed below (Photo 6.41) it was given primary place in the family living room.

Photo 6.41 My brothers and sisters
And this is the picture I took, it was about building your strengths, and um, you know, being strong. These are the korowai (cloak), have you heard of them?... Where the Maori wear them... for special occasions. Yeah, I made four, 'cause, um, it represents, my sister, my two brothers and me...and our culture. The flower represents Samoa, um, yeah.

And what about these, the colours, the blue?

Yeah, that was just the background, of the ocean.

In prison, Galuā had also been approved to do counselling with a psychologist as set out in her home detention plan. She thought home detention would involve “more outings and more programmes” to help her deal with the root causes of her offending. In her disappointed she said that Corrections had failed to be “honest”, as though they had disregarded their moral obligation under the law.

But that, it hasn’t happened, so they, could just be more honest… treat you like, …'cause I like expressing my feelings to, to someone who, you know, who hasn’t met you before, like, or stuff to do with the community.

Over the duration her daughter was undergoing home detention, Tulutulu had no external support as a sponsor (financial, psychological or physical) from Community Probation Service (CPS). In the past Galuā had been a ‘flight risk’ and was used to running away from home. Finding alternate ways of dealing with Galuā’s constant onset of boredom and frustration was the most difficult aspect of home imprisonment which Tulutulu was left to deal with on her own.

I hate, oh, like you got TV and the radio, and more space to move around, but, you know, you wanna get out (giggles) get out of the house, and, go to movies or something, yeah (Second Interview)

Under these circumstances Tulutulu said that she valued the support of friends (see Photo Set, Appendix 8B.2) who helped her to do ordinary chores such as grocery shopping and going to appointments. They also helped to ease Galuā’s restlessness; making her laugh and encouraging her to exercise patience while she completed her sentence.

The thing is now she’s obedient, and that no incidents have happened, it should be the end of it! She should know now, because she’s had enough of staying at home, even though she really wants to go out, she’s, she’s bound here by the thing on her leg. And this is our photo, these are the people, they are, they come a lot and talk and support us.204

204 Galuā, mea lea e iai nei usitai ma aua nei toe tupu seïa mea i luma pea uma nei mea. Tatau na iloa e ia le mea lea ua iai nei auā lē lāva nofo ile fale fia alu e tafao a ua saisaitia le mea lea ile vae. Ma le matou ata lea, tusa o ni tagata nei ole vaega lea, lea o a faapea e o mai tele o taimi talanoa ai foi lele pei support ma (laughing).
Home detention allowed mother and daughter time together to repair their relationship. Having traversed the highest end of the criminal justice system of institutional imprisonment, the family had shifted from the Taigau, (highest point of the wave and the most serious place of the illness).

6.8.6 Stories of other women on home detention

In this section, stories of other women on home detention as described by four key informants are presented. Pu’e’s family members reacted with concern when she started as a prison officer. She felt that the photographs produced from the study could potentially help to demystify the “unknown” aspects of the prison system for ordinary Samoans.

Pu’e: Samoan people...who don’t have any idea what prison is like... ’cause it’s an unknown... Well, prime example, Mum and Dad, you know, “Are, you safe there? Um, what sort of people?” you know. And I’m like, “Mum and Dad, this is where Sio used to work!”...but um, yeah, their perception of prison, was, “O ā tuaina fafine lei iai ? (What kind of women are there?).” “Oh, you’ve got murderers; you’ve got this, that and the other one.” And they, “Oh, okay, okay, you be safe sort of thing!”

Resettlement for detainees back home and the triggers that can remind them of institutional imprisonment were some of questions the Prison officers raised about the study. They also wanted to know the ‘extent’ to which participants appreciated being ‘free’ at home.

Unu: Yes, yeah, definitely...to visualise it, to see it, especially the surroundings, and maybe even having a recording of the sounds too, ’cause prison inside is ugly...You know, just the sound of the keys jingling.

R: Why is that important to you?

Unu: ‘Cause anyone could’ve got it better than them, and if they’re getting it, then they should earn it, you know, they should value it, and think, “Wow, I’ve come off lightly and I’ve got home and here I am! I should really appreciate what I’ve got”. Instead of being in, and looking at those same four walls, Being told to, you know, when to eat, when to sleep, when to get up, when to shower.”

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205 See Appendix 13 for the summaries of each of the key informant interviews. Appendix 14 also describes the backgrounds of three women prisoners (Lupe, Fili and Mina) as discussed by key informant/lawyer Upu.
Samoan mothers, their children and imprisonment

The reality of imprisonment can have an adverse effect on children of prisoners who as a result of their parent’s absence can experience emotional and behavioural problems (6), (229), (230), (231).

One of the advantages of home detention is that it can enable detainees to carry out their parenting “responsibilities” to “appreciate the time” they have with their children.

*Unu:* If they’re mothers that they’re home with their children, and they’re not just sleeping alone worried about them, are they warm, are they tucked in bed, have they have their bottle of milk or whatever but they’re in their arms, that they’ve got them.

If home detention can “lessen the load especially for children”, and reduce the negative consequences of “suffering” on the “entire family” then it should be promoted as an option for Pacific female prisoners.

*Unu:* If they’re home…that no matter if mum and dad are bad, they’re still mum and dad in their (children’s) eyes, and they’re still there with them, doing the best that they can to raise their children while they’re on home d.

Employment is an important outcome on home detention especially if mutual cooperation can be achieved between the relevant parties. Upu’s client, Lupe was sanctioned home detention and permitted to do part-time work with a former employer. CPS installed the surveillance equipment on the premises and ensured that the detainee and the security guards operated discreetly within the workplace. Three key outcomes that were achieved were: paid income for the detainee; time and flexibility for the detainee to do “motherly things” with her children; and thirdly, the successful completion of the detainee’s home imprisonment sentence.

*Upu:* Lupe that was able to work part-time, the fact that they had allowed her that space… it was her own job, it was her own network, her employer was fantastic. Nobody else in the business knew, except the boss and her...But she’d always been a fantastic employee for this particular company…and I thought that was a huge risk, on behalf of the company.

While in prison, detainees can experience high anxiety about the stigma that imprisonment can have on their children. One Samoan prisoner’s anxiety was that her family would “ti’a’i or discard” her child to the “streets” because of the shame and stigma of her imprisonment.
Unu: She talks about, hoping that um, you know her child won’t be teased about her, you know her “sin”, and she calls it, her “sin”…she worries about things that aint even near happening.

Although stress can come from being separated from their children, others resent the partners and the family members involved in their children's day-to-day care. A New Zealand-born Samoan detainee whom Unu worked with complained that her child was being used as a “meal ticket” for her partner and his family to make money from the child support allowance provided by the state. She resented not being given a share of the money. Unu viewed this as an indicator of the prisoner’s denial of the consequences of imprisonment as well as an overall lack of remorse for the crime she committed.

Unu: She’s happy to have these photos in her room, show off these photos of her child, but you know, she’s not there looking after her child, and she’s always moaning...it’s sad that she feels that way... she should be grateful that you know her child’s still within the family, and not with some stranger, foster care, because anything could happen.

6.8.8 Violence

Spousal relationships are important to the quality and success of home detention. Upu’s client confided that her spouse was less violent towards her, because of home detention

Upu: A woman (Fili)...with a Pacific partner - horrendous, horrendous violence! But for her, the home d was actually the protection for her, because he was not allowed in the home...Or if he came to the home, it was actually only to collect the children for contact, so he could only be there for a short period and then he would have to leave again.

The case astounded Upu because home detention provided a temporary protective shield; however, the detainee (Fili) was too afraid to report the violence to the police. More importantly, it posed some serious issues about detainee safety under the jurisdiction of the Corrections department. Being “locked in” and “unable to leave” the house while under duress was a significant problem that Upu identified needed to be resolved within the home imprisonment regime.

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Upu: Fili was stuck in the house and when they would fight, which was often. He, he would leave, she could never leave, because of the serious consequences, um, for her. So it was really stressful, and there were a couple of times there, when, um, there was violence in the home and she couldn’t leave because of the children.

Without adequate intervention, nothing was done to stop the detainee’s husband from being violent, despite the on-going presence of correctional officials.

Upu: In the end, when Fili’s sentence came to an end, he just saw that as license for him to come back into the home, into the relationship, rule the roost, and you know she was so disempowered.

6.8.9 Incest & chronic mental illness

The assessment of home detainees, their readiness for home detention; and the potential risks and barriers that are likely to emerge is a critical part of home detention.

Tao: Um, it just depends. I mean, for home detention, I usually ask the questions “Are you strong enough to be out there without reoffending? Are you strong enough to turn your mates around that getting you into trouble? If the answer’s no, then, it would be best that you don’t look at it, because, you’re gonna be coming in for newer crimes and it’s not gonna get any better. So that’s what you’ve gotta decide, you know, are you strong enough?” And, if they think they’re not, then they’re best to turn down the home.

Mina’s pre-existing issues related to sexual abuse raised deep concerns for the agencies that supported her during home detention. The first sign of difficulty occurred when she named her convicted perpetrator (step-father) to be her sponsor for home detention. The Corrections Department deemed him unsuitable because of his history of sexual assault and she was told to find another sponsor.

Upu: But interesting enough her step-father was more than prepared to be her sponsor, he just saw her as his wife which is quite weird… There was a point where her story almost became unreal because when does non-consent become consent? Because she was still participating in this um, inappropriate relationship with her step-father even after the age of 18…Yeah, so she kind of developed a mentality really and also because she hadn’t really gotten the help that she needed, um, to deal with the, you know, the sexual abuse issues. And because she just told so many lies, people just didn’t believe her anymore…

A significant number of New Zealand prisoners suffer from mental health disorders, including post-traumatic stress disorder, bipolar disorder and major depressive
episode and obsessive-compulsive disorder (6). Mina’s was diagnosed with a chronic mental health condition and being at home reinforced the isolation she experienced on home detention; Upu describing her situation of being “locked down into depression”. Being “locked into a standard three bedroom home, in the middle of the suburbs wearing her pyjamas all day” without any prospect of forming new experiences and relationships highlighted some of the problematic areas of home detention.

Upu: Because you know, for 10 months she wasn’t allowed anywhere and she just became so accustomed to not going further than the letter box…She wasn’t ever gonna go anywhere, people could come over…So when you’ve got no-one to talk to, but the TV to watch and no one’s prepared to listen to you, um, and, even when you tell your story, it almost becomes, um, unfathomable to work out.

Based on her previous work in the forensic mental health services, Pu’e said that many detainees suffer complex issues associated to chronic illness. This is supported by research where many detainees on community-based sentences are reported to have multiple health conditions (232, 233).

R: Do you think there’s a stigma? The same way mental health patients are seen, is there something similar attached to prison, do you think?
Pu’e: Oh, yeah, yeah, yeah, definitely! Oh yeah for sure, but I think [its good] for the likes of the um, [prison] self-care units and when they go out to their outings and stuff, you know on escorted shopping.

6.8.10 Fa’alavelave

Financial contributions to familial obligations called fa’alavelave was something that Foe had to be involved with at home. She spoke candidly about financial contributions for family funerals, weddings and church donations and the expectation to give was like being in a “competition” of “who can give the most”. In her view contributions should be voluntary and based on “giving what you can afford”.

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Foe:  Oh, you know, the ol’ “Your Aunty’s uncle’s cousin’s sister died. You gotta put in!” and the next day…

R:  (Laughing).

Foe:  “Oh, your Cousin’s brother’s sister’s ohhhhh (grinning, making faces), we gotta put in (laughs)! Oh, your Aunty’s Uncle’s sis…” and I said, “Mum, I don’t know those people!” (Laughing)… It’s always something. Or if it’s not family, it’s, “Oh, umm so and so from the Church has died and we gotta put in $500…” I said, “Oh, well we won’t pay your bill! Just, tell them, you won’t pay your bills and feed your kids this week, you’ll just put in for this funeral (grinning)!”

Despite her cynicism, Foe agreed with her mother’s philosophy of the Samoan cultural notion that “you have to give to receive”.

Foe:  Well, we end up always to give, ‘cause I feel bad, you know… Then I’d just, look at it, well, I’m thinking that I’m giving it to my Mum, you know, she can do with it, what she wants with it.

Foe struggled to understand why Samoan families often feel obligated to give their “last dollar” especially to the Church.

Foe:  Mum reckons that’s how we did back then, and that’s how you’re gonna do it, and that’s how your kids are gonna do it. She’s like, “When we have our funerals and that, then you just see it all coming”, you know, “like it all coming back”.

On the other hand, when her grandmother died, Foe saw the power of ‘reciprocal gifting’ that underpinned Samoan fa’alavelave and could not deny that it had some positive aspects.
Foe: Like with my Cousin’s um, and my Grandma’s funeral. Like Mum made it a point, “See we couldn’t of did this without all of our Church Group and our extended [aiga]! Yous moan when they need help. What’s it like now, see?” you know, “All the support and that they’re giving us! And, I don’t wanna hear yous moan about it!” I say, “Oh, yeah, yeah, okay then,” (sighs laughing), “you’ve made your point!” (Smiling)

Upu felt that Samoan families handling of fa’alavelave was sometimes detrimental to their children and saw it as a widespread problem that contributed to Samoan youth offending.

Upu: More often than not, you’ll talk to these kids and all they want is their parent’s attention and time, and they just want to understand, “Why, why do we have to give money for fa’alavelave? Why are you always down at the church? Why do you always have to work?” They just want to understand why...yelling at them, and just telling them to shut up, and blah, blah, it’s just not good enough.

Family financial pressures as well as having the inability or confidence to say ‘no’ resulted in women stealing from their work places and being convicted.

Maota: I’ve noticed, they’re in for fraud, and a lot of reports that I read... the reasons...its family pressure... needing to please the family rather than themselves...if they had a lot more confidence to say, “No, no”...then they can please the family without having to do fraud...but a lot of them were going out to steal money.

Tao was sceptical whenever Samoan fraudsters committed fraud ‘to help their families’. He said that “families are none-the-wiser” and that the crime of theft is entirely ‘self-serving’; having little to do with “taking care of the family”.

Tao: I think initially started like that, but, I think along the way... it got to the case where, “I can do this now. Don’t worry about the family!”...Yeah, it’s theft as a servant. You’re entrusted with other people’s money and you’ve used it for your own things...I know this because they are the ones that seem to reoffend, when caught once.

6.8.11 Summary

The challenges that home detainees have when returning home can often be linked to their previous associations of gang culture, alcohol and other drugs abuse, boredom and the lack of support into educational and vocational programmes. Foe and Galuā completed some of the programmes set out in their conditions and for the most part felt disappointed about the lack of formal support from their probation officers.
Urban youth gang involvement and alcohol abuse, were respective factors in Foe’s and Galuā’s criminal offending. As a consequence, they were required to undergo counseling and educational programmes as ways to address their offending. Returning back to one’s home for completion of a sentence of imprisonment might have many advantages, however, Foe had underestimated negative aspects of home detention with respect to ‘boredom’ and ‘stigmatisation’; factors which seriously affected her confidence and motivation for resettlement in the community. A consistent issue is the formal mechanisms of support from public authorities for home detainees. The effectiveness of home detention can also be dependent on pre-existing problems that in the first place contributed to detainees offending. Key informants highlighted the way that imprisonment can stigmatise children of prisoners and how unresolved issues of spousal domestic violence, incest child sexual abuse and chronic mental illness make home detention a very challenging and complex option under the conditions of electronic monitoring.

Home detention is and can be more challenging than institutional imprisonment and detainees returning home have to deal with the complex issues of spousal violence, chronic mental illness and stigmatisation; making their experiences of imprisonment both oppressive and contrary to the intentions of the state for ‘ease of transition’ back to the community. This raises the question about the obligations of the state to ensure that detainees are protected at their approved addresses while on sentence. In precarious circumstances, detainees can find it difficult to see when progress is being made on home detention. Like the Taifula (tide-wound), detainees need to be able to tell whether the wound is getting better or worse.
7 DISCUSSION

Although the public health and the corrections services operate very differently and have different purposes, participants in the home dialysis and home detention case studies experienced a similar range of outcomes. Following Flyvbjerg (186), when context is closely examined, the results of this thesis indicated that two very different home-based services have several key similarities: the ‘appropriation’ of private household space by State agencies in return for variable levels of support; establishing the built environment as a primary site for compliance; and lastly, the importance of the Samoan culture as a rich framework that families use to help them resolve some of the expected outcomes and added stressors which arise from home-based services.

The State identifies ‘independence’ and ‘restricted freedom’ as key positive outcomes because of the convenience of being home, reduced time and costs of travel, the potential to attend programmes in the community and time with children and family. In the home dialysis literature, ‘self-autonomy’, ‘independence’ and ‘empowerment’ are depicted as ‘good behaviours’ and positive outcomes, which were also considered positive outcomes for those on home detention.

Being ‘independent’ is linked with the patient being ‘empowered’ while coping with and responding to the complications of chronic kidney disease. ‘Restricted freedom’ is achieved through the ‘ease of transition back to the community’ while being electronically monitored. While these outcomes involve some expected physical discomfort and psychological challenges, they are largely influenced by the ‘formal’ and ‘informal’ support received by the state and civil society. Overall however, outcomes associated with health have a much wider public appeal than those linked to justice and court sentencing. Perhaps the key difference between the two is that imprisonment has negative connotations that are associated with ‘punishment’, ‘retribution’ and ‘wrongdoing’; whereas, health connotes ‘healing’, ‘wellbeing’ and ‘assistance’.

As well as discussing some of the added stressors generated from the external obligations of home-based services, the participants’ photographs and perceptions also highlighted a range of divergent and unexpected outcomes associated with
confinement at home. The participants raised issues related to the built environment such as fuel debt, financial hardship, unemployment, mental illness and spousal violence. Surprisingly, these complex outcomes arose despite the fact that public health and corrections authorities monitored participants’ homes through formal house inspections, surveillance and home visits. This raises one of the important questions discussed in the second part of this chapter - is there too little, or too much involvement from the state in the lives of New Zealand citizens receiving home-based services.

In this chapter, which is divided into five parts, I compare my key findings with findings from other studies. The first part looks at the suitability of the houses used for home dialysis and home detention, the unexpected outcome of increased financial concerns after house renovations and issues about safety in the care of those confined at home. In the second part, I discuss the responsiveness of home-based services provided by public health and corrections authorities in the provision of support for rehabilitation, education and employment. In the third part, I consider participants’ use of Samoan cultural traditions, language and gendered arrangements by highlighting the important and relevant areas at the ‘front’ and ‘middle’ of house and the resources that are available to families in coping with home-based services. In the fourth part, I present my reflections on the use of photography for qualitative research, and consider the strengths and weaknesses of Photovoice as a methodology. In the final part, I consider the implications of both case studies for Samoan families and on future policy.

7.1 The Suitability Of Private Household Space For Public Services

7.1.1 Housing tenure

Four out of seven households involved in the two studies, were reprioritised for HCNZ properties, because of socioeconomic hardship, disability, ethnicity, chronic disease, imprisonment, and were families with elderly and children dependents. Most participants claimed one or more income benefits, including the housing Accommodation Supplement provided by the state welfare system.
7.1.2 Building improvements and fuel poverty

Twelve months prior to joining the study, five households had had some maintenance and repairs done to improve their properties for home dialysis, as part of HCNZ’s national renovation programme. Photographs of the interiors of houses produced by participants showed repainted walls, ceiling and floor insulation, refurbishment of existing rooms and structural extensions of additional rooms. As in other studies that have investigated housing improvements for Pacific families in HNZC properties (35, 221) the participants of the study were pleased and satisfied with the changes made to their houses. However, for those shifted to larger, less crowded households, they had not foreseen the difficulty of keeping warm, otherwise known as fuel poverty, discussed below.

Dialysis studies on the impact of housing experiences have highlighted that dialysis patients can suffer poor health when the houses are cold, damp and difficult to warm, especially if the patients are elderly (234-236). In the United Kingdom, necessary housing modifications carried out by borough councils borne by home dialysis patients caused financial, physical and psychological problems during and after renovations. When the National Health Service established the ‘home-based’ dialysis service in the late 1960s and early 1970s, it had to deal with the major problems of the very poor and damp conditions of patients’ houses (235). Delays in building consents approval affected the installation of medical equipment. This was compounded by the associated, but variable costs of renovations across local borough councils responsible for the management of building renovations and municipal amenities such as water, electricity and the disposal of waste. When patients felt upset or treated unfairly because of these housing issues, the hospital renal staff had to find strategies to deal with the conflicts that arose (235).

Because of a HNZC renovation improvement and building programme, three of the five dialysis families (Ata, Efu and Ivi) had had structural modifications carried out which added more light and indoor space to the existing areas of their houses. Despite these positive changes an important theme was the cold that participants endured after dialysis sessions.

Ata’s new found satisfaction with the surrounding landscapes created by the new set of glass door and windows was offset by his kitchen becoming cold from the exposed
winds around his house.\textsuperscript{207} All the elderly patients in the study were extremely concerned about Wellington winds. One such wind known in Samoa is the \textit{Tuaoloa} (Gravely cold) because it is feared mostly by the elderly because of its propensity to cause fatalities.

Coldness was also a theme when Ivi’s HCNZ home which was made larger, after it was merged with another smaller unit. Additional upstairs bedrooms and a larger sitting room downstairs expanded the spatial area, which more than doubled the family’s use of their heaters for indoor warmth. Improvements caused severe fuel debt of around $400 per month. The problem of added household expenditure after housing improvement has long been recognised as an issue in housing policy (McGonigle et al. cited in (237)).

A related study by \textit{He Kainga Oranga} on fuel debt shows that many consumers perceive prepayment to be cheaper, but it is in fact more expensive (56). The death of Samoan woman Folole Muliaga of Auckland, who was unable to use her oxygen machine, after her household electricity was disconnected because of non-payments was widely publicised. As O’Sullivan rightly points out, the predominantly negative and racist media reports of Muliaga’s untimely and tragic death highlighted a strong inclination for ‘individual causal explanatory’ models and ‘self-responsibility’ as opposed to structural determinants of health (238). The switch to ‘pre-pay’ electricity for Ivi’s family led to numerous disconnections, including a serious incident where Ie’s haemodialysis machine stopped operating while she was dialysing on it and she was taken to the emergency department. It is probable that such disconnections happened on more than one occasion.\textsuperscript{208} Elderly participants in particular disliked using their heaters, because of high electricity and gas bills.

Two main explanations for the cold indoor environments were that the pre-50s and pre-70s original house designs do not retain heat and need additional heating. The other explanation is the less effective heating sources used by the families to warm their houses. The participants’ photographs and interviews showed the main heating

\textsuperscript{207} This provided the backdrop to the silhouetted graphically designed picture of Wellington city with haemodialysis machines in Chapter Three.

\textsuperscript{208} It is unknown whether or not the renal unit was aware of the family’s ensuing fuel debt or that they switched electricity providers.
sources were electric oil heaters, and there were very few of these. Of the seven households I visited, only one family (whose family member was on haemodialysis) had a wood burner, which had a higher heat output and a heating duct that warmed the house upstairs.

Several studies on the effects of improving the home 'indoor environment' show that there is a positive effect on health, especially when the houses are warmer and drier. For example, an insulation intervention of houses increased the indoor temperature to 17\(^\circ\)C (41), a study which improved heating, that resulted in a reduction in an improvement of children's symptoms and asthma rates, led to fewer days off school and fewer visits to their general practitioners (57). It also showed energy savings for the households (54).

7.1.3 The suitability of the home

7.1.3.1 Safety issues within the built environment

Another important issue was the physical areas of the house that hindered participants' ability to care for someone with restricted mobility, an issue which was particularly important for the home dialysis case study. Personal care tasks such as bathing and ablutions were particularly difficult because of the old-style shower-over-bath structure. Participants reported sustained back pain injuries from lifting and carrying the patient from the bed to the wheelchair and the wheelchair to the bath. In a study where the intervention involved installation of safety features such as hand rails and the removal of hazards around the house, there was an improved reduction of home injury rates (44). An intervention pilot found a cost-effective reduction of home injury rates. Despite the assistance of external agencies, the caregivers in the study reported that they experienced confusion about their entitlements and felt that the information they were given was adhoc and uncoordinated. Cost-benefit studies of the benefits of care in the home, rather than hospital, do not consider these factors.

7.1.3.2 Storage of medical supplies

A key difference between home dialysis and home detention is the demands on the household to manage the high quantities of plastic and cardboard packaging from
medical supplies. Problems in relation to managing and finding storage space for the medical supplies were reported by most of the participants.

Haemodialysis participants said that they were supplied rubbish bags with their medical supplies, but peritoneal participants said that they had to purchase rubbish bags themselves for the local council rubbish collection. This additional financial cost forced Ofe’s family to collect extra plastic shopping bags whenever they went grocery shopping, to dispose 40 plastic dialysate bags each week. The accumulation of rubbish which was collected each week by local council collectors caused great embarrassment for the family, who felt that a better system was needed to identify medically-related rubbish. The implications of the removal or recycling of some of these medical products and packaging needs better organisational arrangements than the regular domestic rubbish collection.

Ie’s contrasting photographs of the messy laundry at home and the well organised supply cupboard at the renal unit highlighted the stark differences between of home and institution. Accessing medical supplies was problematic, because of the long distance between the downstairs laundry and the upstairs bedroom, and the steep incline of the stairwell. Uso’s suggestion that the district health board could install proper storage facilities that would help patients organise and dispose of their medical supplies more efficiently has definite merits. Storage of home dialysis supplies can be a major complication for patients and their families and should be included as part of the care management (72, 135, 239).

7.2 Responsiveness of Home-based Services

The ‘middle house’ is a very important component of the built environment and provides a useful framework that permits families to contextualise their problems and to respond to some of the complex stressors associated with the imposition of home-based services on family life. In relation to the importance attached to the ‘front of house’, it is the formal part of the house. In the traditional house in Samoa, this would be separate from the day-to-day functions, which are at the rear of the house. It is therefore the appropriate place for the Samoan family, the State, civil societies and private organisations to negotiate the use of private household space for health and imprisonment services. The ‘front of house’ is also, where families interact, negotiate and form links with each other and members of the extended family. This
is important in terms of the resources that become available for home-based services.

7.2.1 Families as an essential component of home-based services

The public health service goals for home dialysis emphasise bringing together the “generalist” and “specialist” clinical workforce, the patient and their family and appear more inclusive than the goals promoted by the justice sector. By contrast, home detention focuses almost singularly on the detainee.

A key presumption is that the mechanisms of support through an individual’s social connections will enable them to meet the formal requirements of home-based services. American studies have shown that health status is dependent on the degree that a home dialysis patient is embedded, or belongs to a social network (240). The contributions that the patient and their family make to a “patient-centred” model are defined as “self-care aspects of CKD and ESKD” and these are developed through their participation and education within the renal care services (p.31 Recommendation 11); known otherwise known as a “patient-centred model” (89) p.31).

Numerous studies have shown that the family social unit can be responsible for generating social capital (Putman (1995) and Coleman (1990)). A general definition of social capital is: “…those features of social organization, such as networks, norms of reciprocity and trust in others that facilitate cooperation between citizens for mutual benefit” (241).

Despite the focus on the detainees, families are recognised by the Corrections Department as important for resettlement and reintegration (46, 242, 243), and an important source of encouragement to the detainee not to reoffend, thereby contributing to the production of outcomes such as economic activity, housing allocation, welfare and health services (46, 242).

Samoan families made many adjustments to cope with, and alleviate, the added stressors of the external obligations from home dialysis and home detention, some of the key adjustments discussed below were made around traditional carer roles, the involvement of children, decisions around death, transplantation and spirituality.
7.2.1.1 Gendered arrangements

The role of care in Samoan families is traditionally taken up by women and young people and this was reflected in the study. However, when two males (father and son) assumed responsibilities for being primary carers, it was in fulfilment of their respective marital and filial obligations. Despite concerns raised by the extended family, this rearrangement of gendered roles, which would not have been accepted in Samoa, was largely non-negotiable because of Olo’s hierarchal status within the family. The family acknowledged that they had greater control and discretion around some of the sensitive gender issues, because they live in New Zealand. Interestingly, a study of patients and their spouses showed that male partners adjusted much better than their female partners to dialysis (244).

Gendered arrangements were also an important issue for those in the home detention study. Foe’s “tidy up” and dismantling of an important communal *umu* was done on the basis of improving the gendered relationships. As the oldest daughter at home she was able to question and challenge the male activities at the back of the house, that interfered with the day-to-day arrangements of the women in the household. In certain circumstances, relationships between family members can improve, because the detainee is at home more (99). Foe’s participation in her family’s affairs did significantly help to improve the relationship with her mother, siblings and extended family members.

Women played a vital role as sponsors in the home detention study through the provision of accommodation and social support. Feminist discourses about the impact of state (public) imprisonment in the (private) home highlight the risks of the inversion of the formal roles of care by the State and the exploitation of domestic labour (111, 119, 122, 123). This is seen particularly with respect to the central role that women tend to assume within families, in which predominantly men, who are sentenced through the court system, become subordinated and taken care of by the women members of the household, who then have the burden of care (120). In home detention the “normal” forms of family life become replaced by unpaid domestic labour (family household members); an inversion of roles between the family and the state, where the carer can be seen as exploited by the state (pg. 76) (119) rather than the state supporting the family.
The extent to which the female sponsors in the study might have experienced exploitation in terms of domestic labour is difficult to determine because Galuā and Foe contributed to the domestic and financial running of their households. Because they were female, it is possible they filled these roles more readily, than if they were male. While feminist analysis is useful, it minimises the complex way in which the Samoan families worked together.

While Samoan masculinity and femininity are recognised through the carer roles, three participants spoke at length about their Samoan traditional *tatau* (tattoos) as inspirational forms of their social and cultural identities. Efu's pe'a provided an important reference of Samoan masculinity against his kidney disease where he, refused to surrender to self-pity, or self-limiting attitudes. In prison, Foe's wrist tattoo was an important reminder of the ceremony that brought nine members of her family together to be tattooed by a master tattooist. Inside prison, her tattoo gave her a sense of composure within a hostile environment. In Samoan culture, the traditional tattoo is a symbol of adulthood and readiness to serve one's community; a person is “clothed” in their genealogy and individuality (168). Tattoos are also used by prisoners to show gang affiliation and prestige, status and rank (90).

**7.2.1.2 The effects on children**

Ivi and Uso’s younger siblings helped out by unpacking medical supplies as part of household chores. Going regularly to the hospital for dialysis appointments gave the children a deep understanding about kidney disease and generated compassion for what their older sibling was experiencing. However, at times the children periodically experienced sadness and stress because of the dialysis routine at home. Psychologist Jeanette Mageo looked at the Samoan ethic where children care (*tausi*) for their elders can lead to feelings of extreme guilt and anguish, to the extent of raising issues of cultural identity. This was found in the case of a young woman who cared for her grandmother on dialysis (245).

The role of dialysis parents is equally important and in the dialysis study, mothers were more active on a day-to-day basis than fathers in responding to incidents of nausea, irritability and depression. Usu admitted that it was very difficult to openly discuss his son’s kidney disease with other family members, while Ivi said that her
husband found it extremely difficult to accept having his daughter’s haemodialysis machine at home. Dealing with a child’s grief of losing their young friends on dialysis was another major task which Ivi had to deal with when her daughter started dialysis at a very young age. All the parents in the dialysis study hoped that their children would be able to have futures of a satisfying career, travel and relationships.

In a study about dialysis, mothers more than fathers of older children (over ten years of age) experienced higher stress and anxiety; whereas, parents of younger children tended to accept the burden of care more readily (246). The demands of administering medications, injections and supplementary feeding and parents’ worries about potential adolescent problems like future aspirations, career and social life.

Living with their extended families meant that Foe and Galuā had day-to-day responsibilities for caring for young children, even while on home detention. Lupe and Kesa were very motivated to complete their sentences on home detention, because they were able to care for their children and hold part-time jobs. Fili, whose greatest fear was that her extended family would abandon her child while she was in prison, was highly motivated to complete her sentence and go back home to care for her. Children can provide positive incentives for detainees to change (247).

Approximately 20,000 children have a parent in prison in Aotearoa (6). Gordon’s Christchurch based study concluded that children of prisoners (also known as the “invisible children”) experience major adjustments because of new starts associated with moving house and schools. Under these circumstances, children often live with their extended families and mostly with grandparents (111).

7.2.1.3 Restorative justice

Two uneasy topics for the home detainees were the impact of their crime on their victims and the consequent loss of freedom through imprisonment. An important strategy that was employed by the detainee’s sponsors was the purposeful discussions about ifoga and the cultural notions and processes of forgiveness and humility as redress for their wrongdoing.
At court Galuā’s family felt deeply dissatisfied that they had made a formal apology using the *ifoga* without the victim being present to hear it. In spite of this major setback, Galuā’s family made constant reference to the *ifoga* in order to reinforce Galuā’s positive behaviours over the home detention period. Foe was encouraged by her mother to see the negative spiritual and emotional effects of her unresolved anger that was a consequence of her crime. Without these internal cultural mechanisms, Foe and Galuā would not have undergone the transition of “reintegrative shaming” that generates disapproval of the person (offender) within a continuum of respect (129). As in other studies, where a detainee’s network of friends and family is an important ‘persuader’ of giving up crime (248), Samoan sponsors were key facilitators of indigenous Samoan restorative justice intervention of *ifoga*.

### 7.2.1.4 Decisions about death, transplantation and spirituality

Samoan metaphors for death and palliative care are embedded in the Samoan built environment. The resting places of those recuperating, dying or suffering from chronic illnesses is known as the house of ashes *fale efu*; the bed place of the deciduous body *fala apulu* and a protective resting place for an afflicted bird *ufuufi o manu gase*.

Palliative renal care is an important part of coping with the disease progression, particularly for patients who forgo dialysis and kidney transplantation. Older Samoan patients found it easier to discuss funeral and burial arrangements with family members. Similarly, Chinese dialysis families are most likely to “share” decision making about medical issues as a collective rather than as ‘individuals’ (249).

Interestingly, transplantation was a difficult issue with most of the older Samoan patients, who preferred to consult a spouse and renal physician rather than their adult children. The main reason for this was to protect family members, even those who consented to be donors, from the potential risks and complications associated with transplantation or the possibility of dialysis if they contracted renal disease. In contrast, younger Samoan patients and their families were more open to searching for kidney donors amongst family and friends as well as undergoing the work-up tests.

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209 Cited in Tuala, based on the work of John Braithwaite.
for transplantation. Often these sentiments were highlighted as participants talked about the photographs of family members displayed on walls and shelves. Personal items such as a perfume bottle, a fine mat collected at a grandmother’s funeral, the shadowy light through a single window and mirrors covered over in the night served as direct reminders of a deceased family member and the Samoan realm of spirituality. Ordinary household objects and the indoor environment mediate the tangible and unconscious experiences of illness and confinement at home.

Photographs of bibles, prayer groups and religious places of worship revealed the social connections to local church communities. In a study of breast cancer survivors amongst rural Afro-American women photographs of bibles and stories about prayer circles were important support networks that sheltered them from isolation and other wider challenges like societal racism (206). Latino participants living with an intellectual disability also identified the importance of social relationships and cultural beliefs in God and traditional health therapies (216).

7.2.2 The advantages of home-based services

When New Zealand introduced home dialysis in the 1970s and home detention in the 1990s, it was partly to resolve the economic and budgetary constraints of institutional health and corrections services. It also followed successive legislative changes that decentralised state provided resources to the private and third sectors. More importantly, family homes were used as formal locations for the administration of publicly provided services, but would increase other advantages such as reduced transportation costs, better employment and an alternative to institutional facilities and workforce.

7.2.2.1 Transportation costs and travelling time

The convenience of being at home was an attractive feature of receiving public services at home for both groups. As expected, the biggest advantage identified by all of the participants was that it eliminated the financial costs for petrol and public transportation and travelling time to the hospital and to the prison.

For the dialysis study, transportation was one of the main aspects of institutional-care that patients complained about. Inexplicably, they were not provided with crucial
information about parking vouchers, travelling reimbursements and free hospital transport available for patients, until several months or even years after they started dialysis at the renal unit. The patient in the study, who lived furthest away (Uso), collected bills of up to $1200 for petrol over four weeks; costs he could afford only because he was in full-time work. The relief of not having to travel to appointments was also experienced by Pacific dialysis patients in Australia who made the change to home (93).

Home dialysis patients, too frail to travel, like Osi’s elderly mother negotiated home visits by the renal specialist. For many families, the choice of home dialysis was motivated to ‘avoid’ some of the inefficient barriers of communication within the public health system.

Transportation became less problematic for Tulutulu, once her daughter started on home detention. Tulutulu could not afford to visit her daughter when she was in jail, because it was too costly to travel and she could not afford overnight accommodation.

Interestingly, the health policies that encourage chronically unwell patients to pursue healthy lifestyles through exercise and leisure, often do not take into account barriers such as high user fees at local recreational facilities, costs of transport and other financial affordability. In a study of women living with HIV, participants experienced major socio-economic changes and poverty, having few resources to get to recreational facilities that could help their health (217). While participants in the home dialysis study could apply for some income assistance from the welfare system, they said they needed more support to be self-reliant and to access relevant resources.

7.2.2.2 Employment

The only two patients to take up paid work and study while on home dialysis were the youngest participants. Carers, (Uga, Ivi and Emo) found it more difficult to resume work and were required to help at home and transportation to appointments. The lack of a link between home-based services and employment mirrored the UK study by Gordon (250), which challenged the claim that patients had retained 55% of their original jobs because of home dialysis. Rather, most patients lost the bulk of their
primary income by 39% and family disposable incomes decreased by 56%. Most patients were forced to find new jobs because their original positions were modified.

New Zealand legislation explicitly states that an offender needs to be “held accountable to the community by making compensation to it” (S26 Sentencing Amendment Act 2007). However, without support from Corrections to advocate on their behalf, both the participants on home detention were unable to secure employment. Ironically, Foe attained regular employment in prison than on home detention. The lack of rehabilitation programmes for prisoners integrated back to the community was a major flaw identified in the first pilot evaluation of home detention in New Zealand (251). Over the first year, six of 21 males on home detention were in paid work, while the female detainees were mostly involved in looking after children, or were pregnant (99). In an overseas study of 20,000 Irish prisoners temporarily released with support for family, work, educational and vocational activities, there was a significant likelihood not to be imprisoned (113).

Paradoxically, neither of the women in the home detention study was eligible for Corrections-funded programmes, because of the ‘66% Rule’, although they were encouraged to find courses themselves. Galuā had the help of her probation officer to secure a three-week life skills course and find suitable accommodation, but neither she nor Foe were helped in any way to find employment.

7.2.2.3 The dominant paradigm of the public health institutional environment

A key philosophy promoted in all New Zealand renal units is, “the more the patient does for themselves, the better the outcome”; it is also a key component of home dialysis (72). The different ways that this is enforced or supported by the renal ward caused problems for some of the participants, who described the dominant staff practice of clearly identifying patients as either “able” or “unable”. Whilst, most patients reported having good relationships with their renal physicians; some had communication difficulties with certain renal nurses. However, this categorisation generated an atmosphere of mistrust and was made worse when the able patients were rostered for dialysis at the satellite unit 20km away from the hospital.

In the context of the 1990’s debates and challenges raised through patient advocacy and the legal challenges that resulted, the complex links between rationing, clinical
decision making and resource allocation were highlighted (71). In 1995, 76 year-old James McKeown received a favourable ruling from the Human Rights Commission that Middlemore Hospital’s withdrawal of renal replacement therapy was discriminatory. The family of 64-year-old Rau Williams argued that the actions taken by Northland Health was a breach of the Treaty of Waitangi, a sentiment that was supported by the Māori Council (252). As Manning et al. points out there is at first glance “disability discrimination” in William Rau’s case and in the context of the disproportionately high numbers of Māori patients requiring dialysis, the issue of equity based on cost-effectiveness formula as set by the health authority raises major human rights issues (253). Judge Salmon’s ruling concluded that it was unclear whether the renal physician’s decision to cease dialysis was made on the basis of a clinical judgment as to Mr Williams’ best interest, or on an assessment of scarce resources that was set out in the hospital’s guidelines (253). Given the hospital’s priority setting around renal services, which was premised on the competitive interests of resource allocation it could be argued that this case was an example where the “public contract model” had led to unpredictable, rather than official expectations (254).

Both of these cases of the late 1990s highlight the complexities of public health rationing in renal care which was not an area of investigation for the study, but does help to throw light on some of the critical issues which affect the health of renal patients and more recently like the Samoan dialysis families in the study. Home dialysis is a much cheaper service to run than hospital dialysis, but is more vulnerable to the domestic environment of the patient’s home. Issues such as fuel poverty, poor housing quality, insufficient heating, lack of indoor storage, waste disposal and high electricity costs seem more relevant yet largely ignored by public health funders. If patients and their families are not being supported enough on home dialysis to cope with the basic areas of care then surely there would be grounds for patients to complain?

In a different study, Pakeha male renal patients struggled with the “optimism” of the “dominant professional viewpoint” in the renal unit, which adhered strongly to the “curative paradigm of biomedicine” (p.49) (255); which consequently resulted in patients struggle with the “ongoingness” and the “uncertainty of dialysis”. Similar concerns were highlighted by the Samoan families who also argued that home
dialysis could be an attractive option for more patients, if several improvements were made to the current model of training, education and treatment. Some of the specific changes were translation of dialysis information into Pacific languages. Finding creative approaches, which employ interactive methods has been shown to greatly benefit patients especially if it helps patients feel that they can attain ‘freedom and control’ from dialysis (256). Samoan dialysis carers also expressed their concerns for more assistance. As Uga and le correctly pointed out, the emphasis on the patient sometimes make carers feel ‘forgotten about’, leaving them to deal with and complain about the formal bureaucratic processes of the public health system.

**7.2.2.4 Severity of the correctional institutional environment**

Key informants consistently commented that home detention can be a much harder sentence than institutional imprisonment, especially if the experience of ‘family’ is negative or not a characteristic of ‘strength’. Spousal violence was also mentioned as a problem for many female home detainees, in spite of the presence of state officials who make home visitations as part of the surveillance regime. Families are observed by Corrections; ‘being at home’ does not mean one can relax or take for granted that home is completely ‘private’.

Within the prison institutional environment violence and stand-offs were experiences for Foe, while Galuā was largely protected from them, because she was on segregated status and prevented from interacting with the adult prison population. Completing their sentences at home removed both women from the austerity of the prison institution, although, the home detention is a sentence was also experienced as being extremely severe because of the expected and unexpected imposition of the loss of freedoms and restrictions.

Payne and colleagues tested Gresham Sykes’s inventory of ‘pains’ and found that home detainees not only experienced deprivation of autonomy, security, goods and services, liberty and heterosexual relations but they also suffered, monetary costs, watching others come and go, and the effects of wearing the electronic monitoring bracelet/anklet (247, 257). Similar differences were apparent with the Samoan detainees.
Detainees of different ethnicities viewed home electronic monitoring more severely than a short jail term of two years on intensive supervision (258). Similarly, being asked to pay a fine of $1,000 was viewed by a quarter of nearly 400 New Zealand prisoners as more severe, than doing a short-term custodial sentence; particularly by those who were unemployed, receiving a benefit entitlement, in financial hardship and had family responsibilities or other commitments (104).

Those who become “sponsors” for male detainees sentenced on home detention, and who are most often inequitably exposed to greater expectations, financial insecurity and deprived of resources, are women (122, 124). Only one local article commented that sponsors received no financial compensation from the state for the care provided to home detainees (121) and called for more research to find the extent this occurs internationally.

Bloomberg’s analysis on home detention uptake in Florida of 100,000 offenders and their families, showed the negative effect of “front-end” strategies\(^\text{210}\) which accelerate state social control by targeting individuals and/or families for earlier and earlier correctional intervention efforts. These measures are typical of the wider decentralisation movement in advanced industrial societies, which have impacted negatively on families through the increased involvement of agencies that work alongside criminal justice, such as mental health, welfare agencies and the larger political economy (106). The author concluded that there are a range of “unintended consequences,” associated with home detention such as: the lack of adequate information and support provided to families; the potential for increased family domestic disputes; neighbour disputes; and new problems involving other family members. Similar differences were also seen with the Samoan home detention study, although, families used their own internal resources to resolve conflict. Female victims of spousal and intimate violence are particularly vulnerable when their spouses (and boyfriend, husband, son) return home to complete their imprisonment sentences to resume family life\(^\text{211}\) (123, 124).

Factors like socio-economic status and wealth of the detainee and the resources available to them can influence public perception about the severity of home

\(^{210}\) Front end are sentences of two years or less and where imprisonment is carried out at the beginning of the sentencing term.

\(^{211}\) Views supported by Sensible Sentencing Trust, Victims NZ, Refuge and other advocate organisations.
detention. Gainey and Payne’s survey of nearly 600 students from two universities highlighted the differences between European and Afro-American minority students. Afro-Americans were more likely to agree that electronic monitoring was an effective punishment (half vs. just over a third), whereas European students (64.6%, n=170) believed that electronic monitoring was too lenient. Afro-Americans were more than twice as likely to agree that electronic monitoring perpetuates a racist system and were more likely to agree that ‘electronic monitoring turns the ‘home into a prison’ (37.8% vs. 30% European students). Half of Afro-Americans believed that wealthier detainees are more likely to stay in nicer houses and this renders home detention unfair (vs. 28.9% of Europeans) (259).

7.2.2.5 Home-based workforce

There are a higher number of staff employed in the institutional public health and corrections workforce, than those employed to work in home-based services for dialysis patients but less so for home detainees. This is because the correctional workforce is made up of both probation officers and private security contractors (Chubbs and G4S).

On investigating the workforce capacity of New Zealand renal units, I found that the main resource management strategy is the frequent employment of part-time staff to fill the rotation rosters. For some of the older participants, being able to establish and maintain a close connection with staff members was important in the renal unit, but this was difficult to do. Whether this is in part due to the frequent turn-over of staff could be a possibility. Two important issues were that no renal staff made visits to home dialysis patients, or could provide translation of clinical information in the Samoan language. If, as research has shown, there is significant reduction of hospital staffing whenever home dialysis increases, then an obvious question is why the hospital service have not made more resources available for home dialysis. The need for better interpretation services would relieve family carers, who are most often burdened with mediating between the patient and clinicians.

In a review carried out by the Auditor General, corrections staff (probation officers and service managers) lacked clarity in relation to procedures. As well as operational failures to routine parole such as timely home visits and planning, staff showed low tolerance levels for compliance tasks that were deemed less critical to
public safety and that this was partly caused by the high numbers of inexperienced staff (260). Detainees in the study were disappointed about the lack of support they received from their respective probation officers during home detention and felt that had their families not been available to assist them to find rehabilitation and employment options they would have been in very difficult circumstances in relation to their successful completion of their sentences.

The failure of home detention to produce the two desired outcomes of decreasing prison crowding and offending rates is another serious issue. Studies show that electronic monitoring is no more effective in reducing offending rates than other prison diversion programmes for non-violent offenders such as drug possession, petty theft, welfare or housing fraud (127) (105). There are major inconsistencies in relation to discretionary decisions in how detainees are assigned home detention especially where the sentence has been used as a “case management device” rather than being applied on the basis of “crime-type and risk seriousness” (128).

Hylton argued that the widespread use of intermediate sanctions (community based sentences) had created a range of undesirable effects on the justice system and extended state control over an increasing proportion of a population (105). He also argues that because of the complex assessment costs and overall expenditures, the operational costs running of community-based sentences can be the same as running “mini-institutions” and cost more to run than prisons, thus questioning both the humaneness and the economics of community based sentences. While the purpose of community-based sentences is to reduce the reliance on the use of prisons or formal institutional settings, my case study was unable to make such comparisons.

7.2.3 Photographic Methodology

Very little information exists about the utilisation of the camera as a tool for the production of research data with Samoan communities and it is and has been well integrated into contemporary Samoan family life for the domestic purposes of recording ‘family events’ (see Appendix 5). The response times between the dialysis participants differed in that the patients requested more time than their carers to produce their photographs because of tiredness associated with their illness and dialysis. Being mindful of wanting to ensure high participant response rates I
maintained constant communication with all the participants and this accounted for the high attrition of participation, where only one participant refused to use a camera. Participants overall welcomed the opportunity to be ‘creative’, although, many said that they were sometimes emotionally triggered about previous events which they tried to capture in their pictures. Baker and Wang also had high participation rates by having a dedicated researcher involved in the follow-up of participants at an outpatients’ clinic for the treatment of chronic back pain (218).

Using a Visual Diary proved an effective way of explaining the research process to participants and helped encourage them to produce photographs about sensitive and taken for granted subject matters. Displaying the photographs inside an attractive photo album surprised the participants and helped to build rapport in the research relationship. I found no other studies that had used a visual diary or the presentation of participants’ photo albums in the same way.

Photovoice emphasises the dissemination of the research findings for the improvement of services and policy and I found that this aspect of the study was a great motivator for participants. This was confirmed when participants of the dialysis study came together for a special dinner to view their photographs and to discuss plans of holding a photographic exhibition, an outcome which was part of the original study design. Consecutive meetings were held for a photo exhibition of the participants’ photographs and these provided on-going opportunities to update them about how the findings of the study had been disseminated to relevant organisations.

Using an iterative approach allowed me to consider the participants’ preferences about the use of their cameras, the length of interviews, gender and cultural sensitivities and whether they wanted to be interviewed with other family members. The photographs were also important material data that supported their stories and helped to build meaning in relation to their experiences of living with chronic illness and incarceration.

Andrew’s Photovoice study on Pakeha women (222) highlighted that Photovoice fails to provide specific guidelines for analysing the “participatory process” outside of that which centres on the presentation and dissemination of research findings to stakeholders (p.42). Andrew followed the Photovoice process of bringing together
participants in small groups to discuss and generate consensus around the themes and meanings of the photographs they produced, a difference with my study where I selected to work only with individuals of each family. However, in agreement with Andrew, I think further research is needed to explore how the participatory process could and should be analysed.

When considering my study against the literature that I reviewed, I found that there are some strong and dissimilar features. Below, Table 7.6.4 summarises some of the key areas in relation to methodology, sample of the participant groups and photographic themes. Given that the studies listed are mostly about health matters, there is a common theme around physical pain and vulnerability. A key theme that these studies all have with my study is “barriers to access” publicly provided services, particularly health care and services like transport and recreational facilities. Closely associated with this are issues of fuel poverty which cover concerns around costs of travelling and coping with basic expenses of managing the home and living. Stigmatisation, which was a theme for nearly all of my participants, is a theme which is often associated with marginalisation and vulnerability. Given that most of the studies listed focus on chronic illness, participants have identified important issues related to the physical pain and, faced at home and institutional settings.
### 7.2.4 Comparison of the reviewed Photomethods literature to my study

#### Table 7-1 Literature vs home dialysis and home detention study

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<td>Oliffe, et al. (2007)</td>
<td></td>
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<td>Singhal, A. et al. (2006)</td>
<td></td>
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</tr>
</tbody>
</table>
7.2.5  Limitations of the study

7.2.5.1  Rich data and sample size

There are several limitations of this study. While the repeated in-depth interviews provided rich data, the greater number of participants in the home dialysis study give greater confidence that saturation was reached than in the home detention, where the relatively low numbers of participants give less confidence that saturation was reached.

7.2.5.2  Paucity of literature

The paucity of literature about the experiences of families living with home dialysis and home imprisonment also make it difficult to determine whether the small sample of those on home detention, while rich, is indicative of others’ experience.

7.2.5.3  Consent

The two case studies, though diverse, were useful in thinking about similarities and differences of the way home-based public services are carried out. Although, obtaining permission was much more time-consuming and complicated for the home detention case study and was less productive in terms of the number of people interviewed, it nonetheless provided illuminating and rich data. However, because of a smaller sample, the results may not be robust as those from the home dialysis case study.

7.2.5.4  Dissemination of the findings

As was highlighted in the Results chapters, the dissemination of the findings is an important component of Photo Voice. Despite my best efforts to facilitate meetings with the relevant agencies who both supported and showed interest in the study, it was difficult to secure funds on behalf of the participants to implement the exhibition project. Producing funding applications was also a lengthy and complicated process which mostly did not provide any financial benefits, except on one occasion where we were supported by the Pacific Directorate of the CCDHB to reproduce the dialysis families’ photographs as a gift to the Minister of Health, Samoa who was invited as a key note speaker to the Public Health Association national conference.
Despite the barriers that are often associated with funding applications the greatest reward for me was the opportunity of being able to work creatively with the participants and to share their excitement and enthusiasm of setting up the project.

Over the last five years, I have made several formal and informal presentations of the photographs and research findings to the relevant agencies which supported or showed interest in the study, including the Wellington Renal Unit and Technical Advisory Services of the Central District Health Boards, Corrections Department and Ministry of Justice. I have made several presentations as a guest lecturer for various national and international social sciences, health and Pacific studies seminars and conferences. Many of the opportunities to disseminate the findings arose from my personal connections with advisors on my Advisory Group and colleagues within the community, for which I am very thankful. The reality however of promoting one’s work and the resources involved in designing and submitting funding applications are extremely lengthy and time consuming. Without a strong vision and admiration for the families involved, it would have been difficult to have sustained the setbacks that I encountered. A major limitation of a participatory research project utilising Photo Voice is the open-ended nature by which researchers are encouraged to disseminate findings to policy makers. As shown by the literature on photo methods, few studies discuss dissemination of findings and rarely mention it. For the families themselves, encouragement and appreciation was often expressed from them for the efforts that I made whenever I presented their photographs in public. In their view, ongoing academic presentation, proposal writing and funding applications are linked to the primary objective of raising awareness about the needs all dialysis families and that this satisfies their own curiosity about the way in which formative research is produced, implemented and interpreted. It also justifies on some levels, their own involvement to share their lives with outsiders for the primary goal of encouraging change, especially to policy makers and practitioners who are responsible for advocating for the rights and privileges of patients and prisoners in New Zealand.

7.3   Future Implications

7.3.1   Implications of the research for the Samoan community

This doctoral thesis has aimed to highlight some of the real and hidden barriers that influence Samoan families’ decision making about home-based services and the
state’s responses to these. In this section, I consider my findings and the future implications of my study for Samoan families and future state policies.

As was shown in Chapter 2, the prevalence of CKD is very high for Pacific peoples; however, the uptake of home dialysis treatment is disproportionately low when compared to Māori and other ethnicities. Home detention rates for Pacific are also relatively low and why this is the case for both of these services is unclear. An issue which was raised by those responsible for the care of dialysis patients and detainees was the need to improve the information about the available support services for families. This includes relevant and culturally specific educational training about medical equipment used for dialysis that would reduce the anxiety of family members at home and increase the confidence about what to do in emergency situations. In order for this to be effective for home dialysis recipients, specialist nurses could be available more regularly to assist at home. This was a recommendation participants felt would reduce patient isolation, improve patient confidence in the dialysis routine and independence and create a better interface with the public health services.

While participants acknowledged the absence of Pacific staff at the renal unit, there was strong opinion that having an ethnically diverse workforce would help relieve families of the tasks of translation.

A major issue is the extent to which families are shouldering the extra costs of care which the hospital system would normally cover in relation to institutional care. Having only one visit from the renal unit was insufficient particularly given the availability of hospital staff and the potential savings from having fewer patients dialysing in the renal unit. One of the key findings is the extent to which family members are required to be involved in helping and ensuring that the home dialysis routine is carried out. Without this assistance, the outcomes associated with home-based services would not be possible and the patient would be forced to remain in the hospital renal dialysis unit or abandon dialysis much earlier if transplantation is not a preferred option.

For home detainees, the regularity of visitations by probation officers was viewed positively and detainees felt that there were many opportunities to raise issues about their sentencing plans through these visits. More problematic however was the lack
of relevant assistance for vocational and rehabilitation programmes which they expected their probation officers to provide. Having adequate assistance through advocacy is important given the issues of stigmatisation that detainees are faced with in the community. But advocacy is equally important as protection, particularly for those detainees living in hostile situations such as spousal violence and poverty; conditions that they should not be exposed to while the gaze of state surveillance is present in their everyday lives. Inside the prison walls of the institution, detainees can reasonably expect the protection of prison officers; home detention sentencing does not guarantee this and if safety is not a condition then it raises the question about whether it should be made available as a sentence. Given the state’s huge expenditure on private security companies for surveillance and enforcement, why is it that more is not done by these specialist groups to help produce safer environments for home detainees and their families?

This doctoral thesis was also and more importantly an investigation of Samoan families housing experiences. Interestingly, families that were prioritised housing by HCNZ for home dialysis and home detention would not have otherwise afforded or obtained a house from the private rental sector. Those that were part of the HCNZ renovation programmes also benefited from having their houses insulated and indoor spaces increased. Private home owners that took up local insulation programmes were happy that the scheme was available, however, like the HCNZ tenants they experienced real challenges of being able to maintain warmth in their houses and this was due to issues of fuel poverty. This has major implications on the increased number of state policies which promote and fund home-based health and correctional services. Greater assistance should be provided by the state for the improvement of heating, insulation and costs of electricity specifically because the houses are being used for the formal provision of health care and imprisonment. Given that patients are already being assisted with being able to purchase certain appliances like a microwave oven to warm dialysate bags; then why would vital heating appliances not be a requirement for those at home in receipt of formal services? With the savings from reduced institutional care, families should therefore be supported to have their physical home environments better equipped to rehabilitate and support individuals who spend a lot of time indoors and are monitored by specialist workforces.
One of the important issues is the role that the family plays in helping to bridge the important transition between imprisonment and release into the community. Without the help of the participants’ families’ home detention and the notions associated with home-based services would be rendered incomplete. If sponsors are a critical component of home detention, then financial assistance by the State could be a way of recognising their contributions in the home detention sentencing pathways. A recent decision by the government has enabled home carers of disabled family members to be paid. This provides a possible precedent for the home carers involved in dialysis and home detention.

An important role provided by family members in relation to restorative justice interventions is the Samoan cultural framework of apologising to the victim and the victim’s family. For detainees who have little understanding of their culture this can be a liberating process and can help build hope for future change. For detainees who have no connection to this framework then the implications can delay progress and require more assistance from the state.

7.4 Conclusion

This doctoral thesis began by the watery edges of the Wellington coast line. It evolved into the camera lenses of Samoan families living in extraordinary circumstances in very ordinary houses. As retold through their brave stories, living with chronic kidney disease and imprisonment is mirrored or reflected in the high and low tides of the natural environment, many of them being created by the moral and political influences that affect them. An important question for this study is whether the home is the right place to resolve the politically complex issues of crowded hospital wards and prison cells; are home-based services the means of achieving this? In short the answer is yes, but an improvement of current services and expanding more resources for home-based services that assist families will be the only way that the State will be able to sustain the increasing epidemic of chronic illness and criminal offending that is on the horizon for Pacific populations.

One of the images that best symbolises the relationship between the state and civil societies is the Tai o alo (Tide of the children) where on the surface the water is seemingly calm but beneath is a ferocious riptide. If the State in its role of leadership is likened to the elder and those in subordinate positions of authority are the children
of the nation, then the riptide that looms beneath is one that imminently threatens those who are the most vulnerable. Without sufficient resources families are exposed to the harshest elements, such is the Taimasatō (Tide-smell-deep); and in spite of their best attempts there is the pervasive frustration where they question whether the Taifula (Tide-wound) will ever get better. Thus is the conclusion of this thesis: *is it high tide or is it low tide, is the wound getting better?* The hope for Samoan families is that there will always be the favourable wind Matagifanua, to bring relief and healing.
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FAMILY-CENTRED HEALING AT HOME:

A Samoan Epistemology of Samoan Families’ Experiences of Home Dialysis and Home Detention in Aotearoa/New Zealand

Matai’a Ramona Niu Tiatia
Appendix 1.5 History of Home Dialysis in Aotearoa/NZ

1960s
- Haemodialysis (machine) first available in NZ.
- All RRT interventions and technologies operational from Christchurch.

1970s
- Home dialysis available in Wellington.
- Increasing demand, shortage of nephrologists and renal nurses, high cost of dialysis services.
- Eligibility for dialysis allowed only for medically ‘able’ and patients aged under 75 years of age.

1980s
- 1982 Department of Health Regulation issued allowing ‘dialysis’ machines to be installed in patients’ homes as “medical appliance”.
- Home dialysis ‘national goal’ within the Service Development Model.

1990s
- Devolution of state health structures to the ‘care of the community’.
- Rationing debates in health sector, renal services & design of clinical assessment framework.

1992
- Public consultation between community groups, health practitioners and renal physicians reaching consensus for ‘more equitable’ access to RRT in NZ.

1995
- James McKeown (76 years old) complaint to the NZ Human Rights Commission withdrawal of RRT found discriminatory on the grounds of ‘age’ in NZ High Court.
- Late 1990s age restriction for dialysis treatment in New Zealand hospitals reviewed and lifted allowing for ‘any’ age.

2000
- All main cities renal wards & satellite centers.

2005-2015
- Rrt expected to grow by 57%.
Appendix 1.6 History of Home Detention in Aotearoa/NZ

1970s
- Correctional Training and Periodic Detention Centers main community-based probationary programme available, especially for Māori and Pacific.

1980s
- Devolution of State operated structures within the Justice Sector: 'community-based' sentences; care of the community; PD and CT facilities closed around country.
- Arohata Women’s Prison replaced the Youth Prison in 1987.

1995
- Electronic equipment piloted with 37 detainees over 3 months in the of the North Island.
- Integrated Model of Supervision introduced 1) targeting high-risk offenders; 2) using pro-social modelling and reinforcement; and teaching and 3) modelling the use of problem-solving techniques and skills.

1997
- Costs of home detention estimated as being equivalent to minimum security imprisonment; ‘economies of scale’ would make it a cost effective community-based sentence.

1999
- Home detention legislated nationwide.
- 893 Orders in first 18 months of operation (General Prison Popn: 5,550).
- Eligibility allowed only for non-violent offences.

2002
- Sentencing Act repeal changed eligibility allowing home detention to an offender irrespective of ‘type of offence’.

2003
- Average number at any time serving Home Detention: 200

2007
- Vaka Fa’aola (the vessel bringing a message of hope and growth), the 44-bed unit at Waikato-based Spring Hill Corrections Facility opened in November the first Pacific focus unit.

2008
- 2,479 Sentenced to Home Detention.
- Sector Response continues to emphasize Prison Over-crowding & Prison as Last Resort policy.
Appendix 3.1.2 Five Most Important Archetypal Samoan Houses

1) **O le fale o Po ma Ao (House of Po and Ao),** “O le fale na ato i tao, ae tulutulu i ulu o tao e faasasaga ifo i le elele.” A house constructed of spears that emerges from out of the ground, for the protection of two sacred fishing and navigational hooks named *Au o Mala* (Cursed Hook) and *Au o Manū* (Blessed Hook) (171) (261).212

2) **House of the Sisters Taemā and Tilafaigā,** “O le Maota o le Tama’ita’i o Taemā ma lona uso o Tilafaiga. O le fale pogisā, auā e leai se tasi na mafai ona va’ai pe ulu i totonu.” The house of darkness, its entrance is securely blocked for the containment of the sacred tools required for manufacturing tattooing instruments, war clubs and the production of *lega* (tumeric for ritualised uses in funerary, tattooing and courtship) (171, 262).

3) **House of the Tuimanu’a, the Fale’ula, that was reconstructed at A’ele in Tuamasaga.** “O le fale tāua na si’i mai Manu’a ma fa’atū i A’ele i le Tuamasaga”. House of governance, the Fale Ula that originated from the descent lines of the paramount King of Manu’a (*Tuimanu’a*) and the paramount descent lines of the Malietoa. The Faleula, is the Samoan social organization representing chiefs knowledge and traditions of which the Samoan culture is underpinned and organised.

4) **The House of Amoa (and Meto), thatched in red feathers and with posts of *toa.*”213 “O le fale na i Amoa e lau i ula ae pou i toa”. This house is symbolic of the governance established by the King of Manu’a in the island of Savai’i in the location near the Pu’apu’a village (169). This village is well known for having preserved many of the ancient Samoan rituals and traditions. It is a story about the non-completed construction of a house, the primary cause of origin was related to the breaches of sacred protocols while it was being built by *aitu* (or equivalent of very small mystical spiritual beings) (171). The house was a

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212 Thanks to Richard Moyle for the manuscript provided on the story of Alo-o-le-la from his archival collection on Samoan *fagogo* which is a comprehensive and detailed version of the story; and at least 10 pages longer in comparison to the version provided in Gatoloaifaana Peseta Sio’s book *O Folauga I Aso Afā*. The entire Samoan collection of the Maori and Pacific Archive of Traditional Music contains numerous versions of each of the five subjects, characters and *fagogo* listed and is well worth exploring.

213 Toa is a native hardwood timber of Samoa.
dwelling of a mythical character named Meto (a supernatural being with the face of a rat and the body of a human being) who gave birth to a boy named Alo, who was later commissioned to build the house that was never finished (173).\textsuperscript{214} The House of Amo is emulated as the most perfect Samoan house.

5) \textbf{The House of One Hundred, the sacred residence of the King of Manu'a.} “O le Maota o le Tuimanu’a, O le Faleselau”. This most magnificent building was constructed with one hundred posts and 100 platform steps (paepae) by the most prestigious carpenters of Samoa. The house symbolises ideal governance and leadership for Samoan society; its origins which were established from the time of the King of Manu’a (263).

\textsuperscript{214} Moyle provides an indepth analysis of a tagi (sung chant) of another version of the Meto story in his book, 173. Moyle R. Traditional Samoan Music: Auckland University Press; 1988...
Appendix 3.2 Five Main Forms Of Tautua/Service

As discussed in Section 3.2, services at the ‘front of house’ differ both in form and context to services at the ‘back of house’ where activities attributed to service of labour and harvesting are carried out (Tautua Matapalapala and Tautua Matavela).

3.2A The Front of House

3.2B Tautua Faiupu

The anterior or front areas (luma fale) are spaces where speech making (fai upu, lauga) takes place. Events such as funerals (maliu), weddings (fa’aipopo), buildings (umusaga), the arrival and departure of visitors (malaga), title bestowals (saofa’i) and the blessings of new buildings are normally accompanied by the acknowledgement of familial and village connections. Orated honorifics are intended to envelope, embrace and transmit expressions of love, respect and compassion along with the ritually significant gifts of toga and oloa. The presentations have significance because of the historical context that gave rise to their origins and formations.215

The services of oratory are important for all Samoan families, particularly during formal occasions and fa’alavelave where Samoan ceremonial ritual involve the exchange of cultural wealth. The ability of being able to speak, communicate and articulate village vestiges are specialist skills used for the benefit of the family within the ‘public sphere’ in the gatherings involving people from ‘outside the family’.

A key component of the ‘fai upu’ role involves the ability to ‘redistribute’ cultural wealth appropriately and fairly. The ability to also resolve and mediate conflict is central to the role of the tulafale ‘orator’ and tamali’i ‘chief’ when they occur within formal and informal settings.

215 Si'il alofa – si'i (to carry, to lift); alofa (love, gifts, cultural wealth). Paole: connection through marriage;
3.2C Middle of House

3.2D Va Tapuia

The 'middle of house' signifies the sphere of family spiritual activity va tapuia and the place of gathering for family prayers ositaulaga. In pre-contact times a magālafu or ta'iāfi ‘fire hearth’ was lit at the ‘centre of the house’ and this fire was kept alight throughout the day and night, primarily this was for the ‘invocation’ of the ancient Samoan ancestral deities; and secondly for clearing odours and moulds from interior timber fixtures. Within this central proximity, the central posts anchored there and the shelving provided in the upper interior region where a family’s cultural wealth was stored (such as ie nofova’a and ie fa’atupu) signifies this area as an important part of the house.

3.2E Tausi Ma'i (Carer of Unwell), Tausi Tamaiti (Carer of Children), Tausi Matua (Carer of Elderly)

Within these gendered arrangements, the formal roles of caring for the elderly, young and unwell (tausi matua, tausi tamaiti, tausi ma’i), preparation of the body of the deceased (se’etalaluma), the upkeep of graves and the interment of the ancestral bones (liutōfāga) are the sphere of women.

As mentioned in the previous section the role of tausi ‘carer’ involves duties associated to the ‘back of house’. However, it could be argued that Illness events are particularly important to the “protective” sphere of the middle house considering the place of prayers, which traditionally were offered over the fire hearth whenever the family gathered. The invocation and signification of the ancestral connections take precedence here in this part of the house.

The long-term accumulation of human and medicinal waste associated with chronic illness and palliative care has distinct linguistic registers within the Samoan language. The word apulu refers to the sticky coating of organic matter caused by perspiration and medicinal applications (plant and oil), which have accumulated over time. The noun equivalent of this word is Apulu tōfāga; a respectful term that refers to the ‘primary site of illness’ of the chief's household (169) which seems fitting considering the primary importance of the ancestor and the fire hearth are both located at the centre of the house. The import work therefore conducted by carers as
part of the back of house function is to ensure that the front of house is protected. This is reciprocated by the functional obligations of the chiefs who *fai upu* (orate, communicate) for the entire family. The functional role of women, traditionally, *fai ‘oa* producers of economic wellbeing. Food, coconut oil, tapa and fine mats are valuable household and cultural wealth. While the production processes women carry out belong to the back of house, they form the important cultural wealth that are stored and valued at the middle house. The interactions and exchanges across all three domains and spaces of front, middle and back have implications on many different levels, particularly with respect to how families prioritise and generate ‘protective’ measures of physical, spiritual and economic wellbeing.
### Appendix 3.3.3 Tides of Samoa – Additional Notes

<table>
<thead>
<tr>
<th>Tide name</th>
<th>Description (Tanuvasa)</th>
<th>Description (Tuitama)</th>
<th>Visual</th>
<th>All Aiga</th>
</tr>
</thead>
</table>
| Taioalo: O le tai e manino luga,  | from above the tide is calm, but is whirling riptide below; pei e agai i aiga po’o e fa’atatau i le aiga: aiga e lelei tagata matatua ae leaga le fanau; related to a family where the elders are wise leaders but the children are weak or visa-versa; below rough, above smooth; can be used to describe a situation that is seemingly peaceful and calm on the one level but is fraught with tension and conflict on the other. | Also the same as: Šema – **await**, Šema sou taeao; Await your moment, or await your time, or opportunity; ia Loma sou taimi, ia Šema sou taimi – meaning wait for the right time.                                                                 |        | • description of renal ward culture  
  • ‘them’ & ‘us’; patients vs. staff  
  • elder Samoan patients & younger patients  
  • struggle of coping with system  
  • transport costs  
  • lack of mutual respect from staff towards patients  
  • cultural misunderstanding  
  • some nurses blatantly unhelpful  
  • Ata & Efu particularly unsympathetic to medical staff  
  • elder members feel entitled to be cared for by staff  
  • elder members not compliant to ‘patient autonomy’ philosophy                                                                                                                                 |
| ae vilivili lalo                  |                                                                                      |                                                                                                                                                                                                                      |        |                                                                                                                                       |
| Tailomaloma: Taimalū              | **Lomaloma: sousou** – waves; **galugalu** – moving quietly but not strongly          | Also the same as: Šema – **await**, Šema sou taeao; Await your moment, or await your time, or opportunity; ia Loma sou taimi, ia Šema sou taimi – meaning wait for the right time.                                                                 |        |                                                                                                                                       |
|                                 |                                                                                      |                                                                                                                                                                                                                      |        |                                                                                                                                       |
| Taisualolo: O le tai ua lolo ma   | **Lolo: u’u** (coconut oil) that has an absolute transparency and ‘immovability’ (**ua le gayoi**), as in the | ***Malū, suau’u*** – oily; you can see it sometimes, when the tide is really calm, like oil on the surface, shiney. Not necessarily brown. Because                                                                                                                                 |        |                                                                                                                                       |
| sua enaena                       |                                                                                      |                                                                                                                                                                                                                      |        |                                                                                                                                       |
### Taifula: Tai e le sua tetele le pe tele

<table>
<thead>
<tr>
<th>Le mautinoa – it’s not known whether it is low or high tide; likened to a ‘fula’ scab that is in a processing of healing; tumau (lasting, continuous) – ua le togafitia; unsure whether the wound is getting better or worse</th>
</tr>
</thead>
</table>

### Taigau: Tai ua faasolo ina maui i tai

| Maūi: natural decrease, diminishing, lessening, withdrawal (ua maūi le ahi); tide that decreases, diminishing ebbs, steady moving seaward away from shore and view; gau: smoothly decreasing or diminishing, differs or is unrelated to figota of gau (harvesting or fishing for gau) Gau: sea anemone (delicacy) leai se atini (no shell) or mollusk sealife that lives below the sand or shielding beneath and ogā niu (at the base of an overhanging niu by the

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| ‘gau’ also means ‘broken’. The tide broken from that of high and diminishing to low; Fever has broken; it has reached its maximum or peak, is diminishing, starting to drop; ua gau fever, ua maūi fever Gau also a sea slug; totolo gau – fish for gau, you feel with the souls of your feet, and can easily tell when you’re stepping on the slippery surface of the gau, by feeling with the souls of your feet even in the dark; |

---

| • spontaneous synchronistic events  
| • shifting of oil in bodywork, muscles and movement are one with breathing  
| • moments of relief  
| • appreciation of expertise & support  
| • tradition of family, leadership role of matai  

| Prolonged waiting hours of treatment  
| • delays in healing  
| • coldness of house  
| • lack of progress  
| • fighting with core Providers WINZ, HNZC, Electricity Co  
| • fights with Renal Unit about times to dialyse  

| • Final recovery, peace restored, completion and rest  
| • steadily becoming easier, reassurance and anticipation of rebalancing  
| • readiness and ease to explore the world anew  
| • Feet first, kicking below the sand, anticipating slimy coldness of the anemone  
| • Hunting with the souls of the feet  
| • hunting in the dark  
| • experience is completely without the need for vision  
| • exploration of the unseen yet a nutritious meal awaits  
| • a harvest for day or night  

---
ocean) and collected easily at low tide by women, found by foot stamped into sand.

<table>
<thead>
<tr>
<th>Taimasatō: Taiua pe eleele</th>
<th>Tō: dead tide, lifeless; separation of tide at lowest level of seabed to create a unique pungent smelliness; likened to the scent of afterbirth discharge when mother given birth to baby</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tō: also means 'pregnant'</td>
<td>To: also means 'sheer cliff or a big/deep hole in the ground. In Lotofaga, two holes close together, inland near coast, one is, Tōsua (sua pe a sua mai le tai, water holding), the other Tōlesua (no water); Not sure if Taimasato is related to pregnancy or sudden drop</td>
</tr>
</tbody>
</table>

- Dead, fluids, recycled, flushed and filtered through
- Waters falling passing through large holes, veins, bags, filtration systems

| to: ua alu ese le sami e aliali mai le matāfaga; ua avese (toese); the tide moves up through to end of the shoreline, reaching to it goes no further and completely disappears, yet giving to the rise and extension of a sandbank or sand dune; a tide that washes onto land continuously for at least 3 hours or more, producing a unique pungent smell that the wind carries |
| Titō –head down first, upside down |
| Taimasa: Tai ua pe elele faatasi ma le aau | Aau (reef) & mata’afaga (shoreline), amu (coral); *aloalo* (reef); Masa: manogi (smell) caused by absence or lack of coverage; exposure to the elements; reef, rocks, reef life and sand exposed to the heat of the sun and creates the pungent smelly aroma; the result of an unusually low tide; lasting 3 hours, occurring usually at half moon, for the duration of 1 week | Smell found in Salei’moa & Malua – like a Sulphur smell (like Rotorua), normally produced by anaerobic organisms and usually associated with an inland (*taufusi*), *e tafe mai ai le vai*; Tamasa is not level, but exposure of the seaweeds to the sun, or vegetation on corals/sand, producing smell. | • Disease exposed; organ depleted of fresh blood • calcifying of the kidney tublar • smelly odours of dialysate solutions • rawness of depletion of life • exposure of the family to harshness of elements • imminent threat |
### Appendix 3.3.4 Winds of Samoa – Additional Notes

<table>
<thead>
<tr>
<th>Faatiumatagitogaina</th>
<th>e matagi a ae fai a faiva o tagata; fa’atautaiga (upu fa’aaloalo for diving) : eg ia e manua le fa’atautaiga, ia e maua ou i’a</th>
<th>Means one is not afraid to say what you say in the heat of the moment; you’re not hiding your feelings or how you feel about it; To go into the rough waters anyway.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>fa’atiu: (fagota; moulu ile sami)</td>
<td>Fagota ile sousou o le sami. Another saying: Fagota I le sao – Sao (mata or fasi laau) e tuitui I totonu ole pu (poking around), e taumafai e tofutofu pe e fa’aosooso ai manatu, testing the other, provoking; Sao fasi laau e fa’aaoaga e fafine I fagota e tuitui ai tama’I pu ile amu (in search of fe’e/pusi); Sao (matatao/ small spear) if you dive with a sao during a lauga (speech), ‘O lea a’u le fagota I le sao, a’u le tofutofua oe, pe alea o’u tautala sa’o ai I le mea lea ou te lagona’, not going to be testing your knowledge; fagota ile sousou o sami</td>
</tr>
<tr>
<td>Matagifanua: agi malū (cool breezes)</td>
<td>of the evening welcomed by the elders while resting;</td>
<td>Ole malū ole afiafi; Ole sau ole afiafi, e malū, e evaeva ile afiafi.</td>
</tr>
<tr>
<td>matagi malū ole afiafi e fiafia ai toeaiina ma lo’omatatua</td>
<td>I Samoa, a e fa’alalā ile ao, e alu loa ile fasa, e o ai loa i fafo, ile sau ole malū ole afiafi; to recuperate, rejuvenate, reenergise themselves by cooling themselves down in the evening</td>
<td></td>
</tr>
<tr>
<td>o le sau, e le gaioi ai la’au (it comes, but doesn’t shift leaves)</td>
<td>very cool and refreshing (with effect of air condition coolness)</td>
<td></td>
</tr>
<tr>
<td>Faasulu</td>
<td>ole afā (storm); fa’atusa ise manatu e malosi; seaward straight ; sulu e fia ola (running for one’s life)</td>
<td>Fa’asulu means ‘persevere, right to the end’; Alu ma alu, alu sa’o iai – straight ahead</td>
</tr>
<tr>
<td>English</td>
<td>Tongan</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>directly positioned from the back</td>
<td>O le a agi fa‘asulu le si‘umouli (name of another matagi) – therefore 'agi fa‘asulu' means 'direct approach' without beating around the bush’ – agi fa‘asulu: going directly to the point;</td>
<td></td>
</tr>
<tr>
<td>Other sayings with similar meanings as ‘agi fa‘asulu’ include: ‘Vili tonu le ifi o Maina,” and “Fana tonu le malama.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>La‘i: wind that comes from the back</td>
<td>“Ua tatā tua o Fatutoa le La‘i o Puava”.</td>
<td></td>
</tr>
<tr>
<td>from behind the back of the houses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e sau fa‘atafa i tua</td>
<td>Beating a dead horse – too late; a wind that has passed by your back, already on its way ahead in front of you</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3.4 *Pu’eata* – Capturing Pictures

![Figure 0-1 Pamela Dalton, Remains of a Wok. Sculpture](image)

**Introduction**

Visual images, their production and understanding are an important feature of this doctoral thesis. In my thesis, I analysed a Samoan *fagogo* (a story narrated and also sung) about an image that is captured in a bamboo cup and an image that appears in a fresh water spring pool (Appendix 3.4 for full description of the story). This story provides a uniquely Samoan perspective about the way water images convey ‘private’ and ‘public’ spaces and the way social relationships within these spaces are given meaning when breaches of customary rights and boundaries within the relationships between *tuaoi tagata* individuals, the and *tuaoi ele’ele* the environment (177).

The story about the captured image and the relevance of water images in Samoan culture; ‘image’ making is embedded within the natural environment and traditionally provided an important way for Samoans to interpret and understand their social relationships within the built environment. The ‘front of house’ (see Appendix 3.2A and 3.4F) and ‘back of house’ (Appendix 3.2Bb and 3.4Da) become the proximal spaces for assessing social obligations and expectations. It is also difficult to distinguish, that which is ‘private’ and ‘public’; what acceptable and non-acceptable norms and behaviours of Samoan social contracts. In the story, the main protagonist
(Sinane’efata) is viewed as failing in her obligations at the back of house, therefore causing shame and dishonour at the front of house and visa-versa. Fagogo are often filled with colourful and spritely adjectives and symbols that indicate health, wellbeing and disaster (Appendix 3.4B). The main moral of the story for the purposes of this component of Samoan epistemology is that human behaviour is both predictable and predicated on norms which both hinder and nurture wellbeing within and outside of the natural environment, hence, the built environment (see Appendix 3.4D for the full story). Tending to all domains of the built environment is essentially connected with all human behaviour, thus, impacting on its associated parts: household social and cultural capital (refer to the figure in Appendix 34C). As will be shown later in the results section, water and healing are closely connected, as are tides and winds, and these connections helped some participants in the study to make sense of their experiences.

3.4A Survey of Fagogo

For ancient Samoans, solutions and responses to day-to-day concerns were readily available through observations of human (tagata), spiritual (tau aitu) and ethological (animal) behaviour that were underpinned by Samoan indigenous paradigms (Va Tapuanu’u) developed over hundreds of years pre-colonisation (264). These complex observations were refined to determine the formal and informal va ‘relational boundaries’ in Samoan society of ‘all things sacred and profane’. From my survey of the Archive of Maori and Pacific Music at the University of Auckland, I found the Sinane’efata fāgogo. There are several versions of this story in the archive, however I selected this one because of the specific references made by the narrator to ata ‘images’ and their significance to the characters and the didactic messages in the story that would have been used to promote certain moral lessons for the listening audience.

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216 Meleisea documents the tensions that exist between pre-Christian and pre-Colonial paradigmatic framework of the Va Tapuanu’u, which is euphemistically characterized as the ‘Era of Darkness ‘Aso o Pouliuli’ and ‘Aso o le Fa’apaupau’, or referenced to the Era of the Days of The Nations Domination by the Spirits, ‘Aso o le Ta’asauali’i o le Atunu’u’, p. 21 and 23.

217 Special acknowledgement to archival librarian Christina Tuitama-Muavi. The archive is one of the oldest known collections of Pacific traditional music in the Pacific compiled by Richard Moyle in the 1960s. Amongst these include chants, songs, oratory from Samoa, Tonga and the Cook Islands.

218 See the Sinane’efata version from Sāle’a’aumua village, ’Upolu, recorded in March 1967 in Richard Moyle’s book of Traditional Samoan Music, p. 64. The fagi differs slightly to the version I have analysed in this chapter.

219 Ata (1. a shadow. 2. The morning dawn. 3. a spirit. 4. The emblem or representative of an aitu).
3.4B  Fagogo

The Sinane’efata story is a Fagogo, a storytelling performance form which like other Samoan linguistic and oral traditions transfer the knowledge frameworks of va tapuia ‘from the ears’ tala tu’u taliga from one family to the next. “Fāgogo, although fictional in nature, allude to real place names, objects, or events which narrators may stop to accentuate and clarify during their performances” (173). They often contain a sung chant (tagi) that conveys sometimes contradictory themes and questions about everyday aspects of Samoan life” (p.57) (173).

A fagogo is usually told to family members at the end of the evening (265)) and contain moral and practical insights for the listeners.

3.4C  Water images in Samoan story-telling

Aquatic symbolism related to water is found universally in religious and cultural practices around the world, and reflects the vestiges of ancient folklore which have survived through industrial civilisation (266). From these oral traditions, water is strongly associated with beginnings of the cosmology which have provided complex meaning frameworks to explain the human, religious and cultural experiences related to ‘birth, baptism, death and healing’ (267). Pacific mythology and oral histories also provide clues and insights to actual historical accounts for the emergence of land mass formations in scientific investigations. Maui, Tinilau, Tagaloa and numerous other mythical and supernatural heroes are associated with the creating or co-creating islands and mountains through the supernatural acts of “fishing” lands and atolls up from the depths or “throwing” them down from the heavens (1). Water images highlight the importance of water to the natural environment, symbolising and signifying the ‘sacred order of relationships’ within Samoan cosmology otherwise known as va tapuia and the protocols of protection linked to land sites such as caves, spring pools, coastline rock formations and mountains (164).

In the healing work of Samoan traditional healers water is recognised as being able to have magical and supernatural power, the same way that certain medicinal herbs

220 Fāgogo are told for the entertainment and instruction of listeners regardless of age or status. Not a “blueprint for human behaviour, the fāgogo presents dichotomous themes about culturally acceptable and unacceptable behaviour played out by humans and non-humans (ogres)” (Moyle 1988).
and rituals do in the diagnosis of a person’s illness and the detection of one or several aitu (spirit entities) (23, 245, 268). Water in other cultures and religions as a way of ‘intensifying’ and ‘invigorating’ human life by “descending into, sprinkling and dipping into it” (269). Christian religious doctrine and practices rejected the indigenous veneration of ‘supernatural beings’ in iconic objects throughout the Pacific (270, 271) and was an area of every-day life that was monitored, normally with disapproval by Christians missionaries (272). Turner reported in the late 1880s that a spring pool was filled with a large rock to prevent Samoans from visiting and summoning ‘spirits’ reflected in the water (163). This story is another version of the Sinane’efata story retold here. Interestingly, the practice of covering mirrors in European households stems from folklore beliefs and superstitions of objects ‘capturing’ the spirit of the dead and becoming haunted, a practice which was taken up in Samoan households.

3.4D Pu’eata – Caught Pictures in the Sinane’efata Story

The Sinane’efata story centres around two sisters Sinale’un’unu and Sinaetevālo. The sisters, as part of a caughting ritual to secure the hand of a beautiful woman named Sinane’efata (Sina, a female archetype found in Samoan mythology; ne’e, proud, arrogant; fata, raised shelf) set about to pu’eata ‘capture’ their brother’s image by filling it a bamboo cup ofe with suāvai ‘water’ and then later transferring...
the image to a water spring pool.\textsuperscript{227} It highlights the sister’s attempts to establish themselves within the village polity through upward social mobility. The narrator of the story makes specific reference to the \textit{pu‘eata}\textsuperscript{228} describing it as an ancient way of producing images (\textit{preCamera})\textsuperscript{229} Their brother’s name was \textit{Maluofiti} (\textit{Malu}\textsuperscript{230} ‘protector’, ‘guardian’; \textit{o-fitī ‘of Fiji’}\textsuperscript{231}).

The captured image, in the sister’s possession was taken everywhere they travelled for the express purpose of finding a suitable partner.\textsuperscript{232} When the sisters arrived at Sinane’efata’s village they transferred the image into her pool (\textit{vai ta’ele ole tama’ita’i})\textsuperscript{233}, reserved only for high-ranking families.

In fielding numerous gifts and proposals for her hand in marriage, Sinane’efata’s rejected all but one suitor, a cunning trickster named \textit{Tigilau} (a renowned mischievous and fabled character in Samoan storytelling).\textsuperscript{234} He came bearing nothing more than a \textit{tapu vae ‘pig’s trotter’}, a gift hardly befitting of Sinane’efata’s status, but one that she seemed satisfied with. It forewarns the audience that there

\textsuperscript{227} Given that the \textit{pue’ata} produced by the sisters would fit within the gendered arrangements surrounding cultural wealth for women (\textit{toga}) and men (\textit{oloa}). This is compatible with this idea, that the \textit{pu‘eata} has been connected to the much complex system of ancient Samoa known as the \textit{aumoega} (courting parties) but the derivatives of the words \textit{pu‘e and ata} have wider applications in numerous contexts.

\textsuperscript{228} Story-teller: “\textit{O aso anamua, e ‘avea ma mea pu‘e ata i - ona e tatau e pu‘e le ata o le tama, ‘o le tā le ‘ofe, fa‘atumu ma le suávai e maau ai le ata o le tagata. E fa‘atū ma fa‘afo‘i ai le ata o lelā tuagane, ona ua o lea ma tenei e aumomoe.”}

\textsuperscript{229} \textit{PreCamera}, a term I use here which depicts an indigenous understanding of how images from the natural environment are used mediate and analyse social relationships and objects.

\textsuperscript{230} \textit{Malu-o-Fiti}: \textit{malu} (also means gifted, heroic or honourable one and renders to service \textit{‘tautua’ or attendance}). Political exchanges were built among the Pacific nations within the region particularly marriages between Fiji men and Samoan women.

\textsuperscript{231} For example, in various geographical sites and villages throughout Samoa there are links to a Fijian woman known to have presented prestigious gifts of various fish species to different hosting families: the \textit{tule} fish special to the village of \textit{Āsau}; the \textit{anae} (mullet) to \textit{Pu‘apu‘a}; and the \textit{manini} to \textit{Auala}. It is possible that the story has links with Fiji and that the pool signifies an important gift or political alliance (\textit{malu}) between the characters of the story (Tupuola Malifa, personal communication).

\textsuperscript{232} \textit{Pu‘e} used normally in reference to an animal or person being ensnared, caught or trapped, particularly in the context of hunting or pursuit in competition. A somewhat euphemistic term used to court a suitable match for marriage as the sisters were trying to do for their brother. \textit{Fagogo} often characterise a young woman as a bird, like a pigeon or lupe ensnared as such by its captor, nurtured or sometimes set free. Here it is a male contained in a small cup and later in a communal spring water pool.

\textsuperscript{233} \textit{Vai ta‘ele ole tama’ita’i} (Bathing pool of the Young Woman). Story-teller: “\textit{Ua tata‘e le ata a le lā tuagane i le vai o le tama’ita’i}.”

\textsuperscript{234} Tigilau is a frequent character not only in Samoan stories but throughout the Pacific with various names, such as Tigilau Ti‘eti‘e and Maui Tiketike. In this story, while \textit{Tigilau} and \textit{Maluofiti} appear as separate characters, it is possible that both are one in the same personalities, each forming the duality of negative and positive, good and bad, mischievous and polite. \textit{Tigilau} stories abound in Moyle’s archival collection.
are hidden paradoxes and that the characters are about to be exposed for behaving ‘improperly’.

One day, Sinane’efata went to her special fresh water spring pool\(^{235}\) to bathe (\(\text{ta’ele}\)\(^{236}\)) with family and friends, when Maluofiti’s apparition appeared intermittently and she became curiously attracted and overcome with love for the image. Each time the image appeared, Sinane’efata was lured by the haunting tone of the \(\text{tagi} \) ‘chant’ that was sung.\(^{237}\) She went seeking the image day after day as the sisters watched on. After failing to invoke the mysterious apparition into a ‘humanly’ form, Sinane’efata issued a public proclamation and enlisted the help of the men of the village (\(\text{malosi ole nu’u}\)) to find lost image. She promised a great reward to the person who could help bring her and the image together, despite the fact that she was already betrothed another, making the events at the pool even more scandalous.

\[\begin{align*}
\text{Ole manaia e mafai, ona gaoioi, (The young warrior that can move, shift)} \\
\text{pe liliu ai le ata lea o lo’o i le vai, (or turn the picture in the water)} \\
\text{O ia lava lea o le mā e fa’aipoipo, (then only will we marry)} \\
\text{po’o o le mā e nonofo fo’i." (or live together)}^{238}\end{align*}\]

Watching from a distance the two sisters felt aggrieved that Sinane’efata had acted with inappropriately and without fidelity; indicated by the narrator’s words: “\(\text{Ua mutia le fanua ma palapala i le va’ai o le ‘au uso’ the land is overgrown and muddied in the view of the sisters’}.^{239}\)

On the third and final chant of the \(\text{tagi}\),\(^{240}\) the sisters summon their brother to appear. It is an important moment in the story where thematic dichotomies between culturally acceptable and unacceptable behaviour are revealed (173).

\(^{235}\) Spring pools (for example Vai o le Tama, Mata’a’afa; Vai o le Teine, Sina) were often the result of successful courtship alliances; the village pool site becoming a macrocosmic communal representation of a family progenitor. A dedicated communal swimming pool like the one in the story could easily be an example and, because of its significance to the village, may also be restricted to certain families of rank.

\(^{236}\) \(\text{Ta’ele} \) (Bathing) has associative links to funerary rites of \(\text{liutōfāga}\), the exhumation of bones and interment to another grave. It also refers to the belief that the removal of disease or contagion from a deceased person by invocation through supernatural means or purification by fire will prevent its spread to other living family members (Pratt).

\(^{237}\) The \(\text{tagi} \) is sung three times in the story.

\(^{238}\) An alternative translation provided by Richard Moyle is: Sinale’u’unu, Sinale’etevā, I miss my dear brother, Lemaluofiti, do get up – it’s daylight, And your reflection is hardly respectful!

\(^{239}\) The sisters in discussion with one another, having assessed the events at the pool, agreed it was timely to intervene, “\(\text{Sau ia, sau o le mea tonu, sau, e tatau ona tā 6, fa’aalaima a le tama’ita’i a le tā tautane’} \)” (Come now, it’s the right thing to do, come, we should go and reveal/present Sinane’efata to our brother).

\(^{240}\) Something which he does fairly promptly in his \(\text{paopao} \) (canoe), a feat which Sinane’efata ironically was unable to achieve.
Sinaleu’unu, Sinale’etevalo
Ta tuagane, tagi sā (Our dear brother, we weep for him)
E’i’ai ona ta fa’apenā (It’s why we are feeling this way)
Lemaluofitie!
Ina tu taia ua ao (do get up from the shallow water – it’s daylight)
Ma lou ata ua fa’alemigao (And your reflection is not being honoured).241

Heeding his sister’s call, Maluofiti finally emerges from the water in human form, much, of course, to Sinane’efata’s surprise and dismay (because she was unable to summon him). His first words are to his sisters, asking whether Sinane’efata had taken care of them while he was away. The sisters are candid in their response and tell him they were ‘mistreated’ (“sā faį leagaina mā’ūa” ‘we were treated very badly’ i.e. not treated according to their station and hierarchy)242. This resulted in an unfriendly rebuke of Sinane’efata,243 who was hurled insults and then abandoned to her death as she tried swimming to catch up to the canoe with Maluofiti and the sisters in it. Sinane’efata’s was turned (liliu) into a pillar of coral, the lasting reminder for all who see it of the tale about a watery image that could not be made real.244

3.4D Analysis of the Story

At first it would appear that the story is simply one of infidelity and betrayal of social norms, particularly with respect to Sinane’efata’s betrayal of her betrothed Tigilau. However, a more critical analysis show that the elements of ‘trust’ and ‘care’ contained in the ‘private sphere’ were altered dramatically in the ‘public sphere’ when breaches of trust occurred.

241 Thanks to Richard Moyle for the original translation of this tagi. After rechecking the recording, I changed lines 2, 3 and 6 slightly for a more clearer description.
242 However, both sisters implore Maluofiti to show empathy and mercy towards Sinane’efata for her lack service.
243 As the group make their way to the canoe, the sisters attempts to calm Maluofiti’s anger could not be appeased: “E lē avea le ta’u valea o a’u ma mea, e sui ai le’aga leaga, le ‘aga pua’a ia te’i ‘oulua! Leai ő mai ‘oulua e feosofi, ‘ole ā tātou ő”. Translation: “Nothing could be worse to me than her disgusting mistreatment shown to the both of you, like a swine! No, climb aboard, let us go!”
244 Coral (aro) blocks are traditionally used to line graves in Samoa but in the story the coral pillar signals Sinane’efata’s death, which the storyteller explains can be still seen in the village where story originally comes from.
The sisters’ protection of their brother’s ‘captured image’ pu’e ata suggests that, this was a story about the recognition of the ‘sisters’ as feagaiga; the fullest expression of the feminine principle and characterised by the socialized roles of the healer, teacher, priestess, wealth maker (faioa) and peace maker (pae ma le auli) as recognised within the fa'amatai, nu’u o tamai’ta’i (164). As shown in A.1 Figure (above) social capital and cultural wealth (capital) are determined by a person’s private demeanour (image of the cup) and their public behaviour (image of the pool). Often, as depicted in the story, it can be difficult to distinguish private and public; microcosm from macrocosm; real and unreal; waking and dreaming. The chant of the tagi in a fagogo, should help one to reflect inwardly and outwardly about the consequences of one’s actions and how they may or may not influence Samoan hierarchical and proximal spaces and relationships.

3.4E Front of House in the Story
Each of the characters is endowed with human frailties which make them vulnerable across the private and public domains. The sister’s pettiness as indicated by their names amplifies the potential consequences of families failing to fulfil their own
mutually agreed protocols of respect and reciprocity with ‘outsiders’. Tigilau’s miserly gift should have forewarned Sinane’efata against making a formal alliance and a long-term obligation to the sisters. She also developed delusional fantasies of love for Maluafiti’s watery image, which in reality resulted in his complete disregard and neglect of her, revealing him as a man who lacked any authentic commitment to show leadership on his part.

3.4F Summary & Analysis of the Pue’ata Story

An important theme is the sister’s allegations Sinane’efata’s neglect of duties care towards them, however unrealistic or unfair. Ironically, as mentioned before, her choices of forming an alliance with an outsider was based on the ‘surface’ who seemingly appear ‘generous’ but are in essence mean spirited and untruthful. Such is the nature of social contracts that families make with ‘outsiders’. What may seemingly appear to be ‘ideal’ on the surface within the public domain (watery pool image) can in fact be less than desirable within the private domain (watery cup image)? The mismatch between Sinane’efata and her sister-in-laws highlights the themes of improper behaviour (vindictiveness and manipulation), an inherent and problematic component of social contracts and alliances endemic of human behaviour and societies.

The moral and message of the story therefore ends by showing how offences at the front of the house can impact behaviours and norms at the back of the house. The Pu’eata story has implications for how ‘social and cultural capital’ is generated by Samoan families, particularly when there are expectations and alliances with others outside of the family. This framework of understanding can help contextualise some of the sensitive issues which Samoan families have to manage in relation to working with others outside of their family such as work colleagues, friends, state and civil organisations. This may also help to provide some important insights about the way that families of the study dealt with the institutional arrangements of home dialysis and home detention. As will be shown later, some of the protocols highlighted in this story, particularly with respect to reciprocity and the obligations of care are reported in the experiences of the participants of both studies.
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ARTWORK
Paintings: Stevenson Retimanu-Pule (14 years old); Ingrid Gottlieb, Si’ufaitoto’a Simanu Ieremia
Graphics: Tiana Tiatia (16 yrs old)
Photographs: Participants of the study. Dialysis patients & carers. Home detainees and sponsors.
## Appendix 4.2 Reframing of Case Study Method

Flyvbjerg's Reframing of the Case Study Method

<table>
<thead>
<tr>
<th>Common Misunderstanding</th>
<th>Should Be Replaced With:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 General, theoretical (context-independent) knowledge is more valuable than concrete, practical (context-dependent) knowledge.</td>
<td>Predictive theories and universals cannot be found in the study of human affairs. Concrete, context-dependent knowledge is, therefore, more valuable than the vain search for predictive theories and universals.</td>
</tr>
<tr>
<td>2 One cannot generalize on the basis of an individual case; therefore, the case study cannot contribute to scientific development.</td>
<td>One can often generalize on the basis of a single case, and the case study may be central to scientific development via generalization as supplement or alternative to other methods. But formal generalisation is overvalued as a source of scientific development, whereas “the force of example” is underestimated.</td>
</tr>
<tr>
<td>3 The case study is most useful for generating hypotheses; that is, in the first stage of a total research process, whereas other methods are more suitable for hypotheses testing and theory building.</td>
<td>The case study is useful for both generating and testing of hypotheses but is not limited to these research activities alone.</td>
</tr>
<tr>
<td>4 The case study contains a bias toward verification, that is, a tendency to confirm the researcher’s preconceived notions.</td>
<td>The case study contains no greater bias toward verification of the researcher’s preconceived notions than other methods of inquiry. On the contrary, experience indicates that the case study contains a greater bias toward falsification of preconceived notions than toward verification.</td>
</tr>
<tr>
<td>5 It is often difficult to summarize and develop general propositions and theories on the basis of specific case studies.</td>
<td>It is correct that summarizing case studies is often difficult, especially as concerns case process. It is less correct as regards case outcomes. The problems in summarizing case studies, however, are due more often to the properties of the reality studied than to the case study as a research method. Often it is not desirable to summarize and generalize case studies. Good studies should be read as narratives in their entirety.</td>
</tr>
</tbody>
</table>
Appendix 4.3 Camera in History and Samoan Images

4.3.1A Introduction

In this section, I discuss some of the historical background that gave rise to the various uses of the camera, and highlight the role of the ‘colonial photographer’ as a producer of images of Pacific peoples until the invention and the distribution of the camera became widely available as a consumer product to the masses.

Pacific historiography of recent years has challenged a range of mistaken classical notions and stereotypes about Pacific indigenous peoples that became reconfigured by colonial commercial and scientific developments (22, 187, 273-289).

Disagreement varies amongst post-colonial scholars about the colonial stereotyping promoted through photography. Academic discourse challenging the two hundred year’s history of colonial notions and representations of Oceania’s Pacific peoples has steadily increased in post-colonial and post-modernist thinkers of Pacific histiography since the 1970s. In Figure A (below), I have summarised the various discourses associated with the photographic imaging of the body, stemming from western epistemologies.
4.3.1B The inferior senses of the natives

Western hegemonic discourses have shaped the human body and how it is conceptualised within the formal criminal, social and medical settings. The way that the Pacific body has been conceptualised since colonial contact has relevance to Samoan peoples’ participation within the New Zealand public health and justice services sectors. It is difficult, therefore, to write about contemporary photographs of Samoan people collected through a study like the one that I undertook, without considering the extensive two hundred years of European historical discourses promulgating Pacific indigenes of the Oceanic nations as “noble savages”; an image distributed worldwide by photographic and film media.\textsuperscript{245}

Howe’s survey of Pacific historiography and literature of the 1800s and 1900s reflect the dominance of European romanticised views about the Pacific peripheries that still continue (27).\textsuperscript{246} These begin and extend beyond the journal writings of two French


\textsuperscript{246} Howe’s work broadly defines two categories of writers responsible for the amassed volumes about the Pacific since the Enlightenment to the present. The first category includes ‘fatal impact’ writers criticising destructive forces of industrial capitalism in the Pacific. The second category consist of the Modern school of Pacific historians that reject notions of Fatal Impact - substituting the image of an active, initiative-taking savage whose way of life was not necessarily ravaged by European contact.
explorers, Laperouse and Dumont d'Urville of the late 17\textsuperscript{th} century who provided the world with the earliest journal description about Pacific peoples and Pacific protocols. After the explorers were presented with gifts by Pacific people, they proceeded to reduce the significance of “cloth”\textsuperscript{247} and the hierarchical complexities associated with Pacific gendered arrangements, to mere sexual commercial exchanges (290). Like other navigators after them, they had based their observations on the deeply racialised ideology of the “civilized/Christian whites bringing light to the savage/heathen” (277), although it has to be acknowledged that other colonial navigators to the Pacific like Captain Cook reflects that there were more complex issues beyond this.

These negative descriptions continued during the first globalisation from 1870 to 1914, as new territories were forged by shipping lanes and rail routes and as more traders, missionaries and navigators travelled throughout the Pacific (14). As more Samoans ventured out into the world, the first images of them were captured as portraiture photographs at ethnographic world fairs and expositions of the late 1800s and 1900s. Christened as “world universities” (291) for championing innovative commercial modern inventions, the fairs were also places for the systematic use of film in anthropology. Film archives were built around the exhibitions and ‘displays’ of indigenous peoples for the European and American masses who paid tickets to watch and observe (275).

The first ethnographic moving film (chronophotograph) was produced of an west African woman by an anatomist studying cross-cultural movement at the 1895 Paris World Exposition (289). Nearly 100 million Americans between 1876 and 1916 visited international expositions and many more millions in Europe.\textsuperscript{248} Scientists who could not afford to conduct field research abroad prospered most from ethnological exhibitions, by carrying out experiments and surveys with the travelling performers of diverse ethnicities (275). Samoan performers were amongst them, having joined up to official tours arranged by colonial administrators and merchants. Photo A5.1 is a portrait of a Samoan troupe that travelled to the 1899 Moskauer Panoptikum,

\textsuperscript{247} Cloth (industrially manufactured or unprocessed plant fibres) denotes the ritual artefacts and iconography in Pacific cultures. In Samoa this refers to ‘siapo’ and ‘tapa’ (mulberry bark), ‘toga’ (pandanus fibre finely woven mats).

\textsuperscript{248} A chronophotograph

\textsuperscript{249} pg. 2. These account for audience participation numbers at international expositions held at Philadelphia, New Orleans, Chicago, Atlanta, Nashville, Omaha, Buffalo, St. Louis, Portland, Seattle, San Francisco and San Diego.
Frankfurt in Germany. Display signs and newspaper sensationalized the troupe with ethnographic ‘typologies or types’ put together by scientists, traders and missionaries of the day. To attract ticket sales the troupe was advertised as: “breathtakingly beautiful, always cheery, erotically permissive, lazy people from the paradisiacal Pacific Ocean” (p. 343) (277). Elsewhere in the same advertisement they are described as “wild beasts (wilde Weiber)". In the booming tourist postcard trade which lasted for nearly 200 years, images are framed with a distinctive iconography of “short raffia skirts, long and loose hair”, and “a thin lei...leaving the breasts exposed” (292).

![Photo A5.1 Samoan Troupe in Germany Plakate 1880-1914:257, cited in Corbey 1993:343)

Although, ethnological expositions in their heyday ran for nearly half a century, their popularity declined by the 1930s, partly as the result of numerous photographically illustrated publications that flooded the consumer markets produced by numerous scientific and pseudo-scientific anthropological organisations; and partly because of public and political objections that viewed human displays as immoral and exploitative (277)(p. 358). Indigenous performers often died and suffered from homesickness, vicious infections, emotional confusion, difficulty in adjusting to the European climate and food. The use of photographs, as with colonial and missionary propaganda films, took over much of the function of ethnological exhibitions (p. 348).

249 In the World Expositions cited here, the Samoan dance troupes are travelling under the auspices of Trusteeship of Friendship in which Samoa’s mandate and trusteeship was shared between America, Britain and Germany from 1888 to 1889. 250 [Footnote: the early use of the term haole meant foreigner (Tu ole, or “without breath”, that is, without an understanding of the Hawaiian culture) - Virgina Dominguez: palagi: cargo/cloth]
Scientists like British zoologist Alfred Cort Haddon, led film expeditions overseas in order to demonstrate categorically that the “lower senses and animalistic traits” were biologically determined in native savages like the Torres Straits Aboriginal Australians (192). Hawaiians (according to phrenologist Samuel Bell) were deemed unfortunate because of their skull size and cranial shape; however mental adeptness and admirable beauty put them “higher up” the hierarchy in relation to other supposedly inferior peoples (the Puerto Rican, Melanesian and Malay) and “lower” than the Tahitians (292). If “photographic literacy is learned” (293) then what is distributed about Pacific peoples is that their traditions, which are passed on to the “ear” (tu’u taliga) and through the natural senses of smell, touch, sweat, sight and taste are defined as inferior within a Western paradigmatic framework.

4.3.1C The criminologists - photo as legal document

As industrial cities expanded all around the world biometric typologies were also used to categorise ethnic populations, mostly migrant strangers from rural townships and foreign shores, who provided labour and sweat in the construction of roads and cities for Western civilisation (294). In this environment, the camera was used increasingly to emulate the ruling classes’ dominion of “intellectual over manual labour” and to protect their private property and capital. As a “visual document” the photograph could denote “legal status of ownership” and provide evidence of missing property and grounds for a complaint to judicial authorities (293).

By the 1860s, police within metropolitan urban cities increasingly used the camera as a formal record of indexical statistics where scientists (anthropological societies and museums of natural history; physiognomy and phrenology) and law enforcers (criminologists) collected permanent images to categorise both the ‘criminal body’ commonly known as the ‘mug shot’ and the ‘medical body’ (295). Of note, but rarely acknowledged in histories of photography, were the major contributions of three scientists, responsible for elevating the photograph as ‘evidence’ grounded in abstract statistical methods: Alphonse Bertillon, for combining photographic portraiture, anthropometric description and highly standardised and abbreviated written notes of criminals on a single fiche or card; Adolphe Quetelet, an early

252 Bertillon had enlisted the help of Adolphe Quetelet to identify 4,564 recidivists by systematizing police records collected from 1883 and 1893. Bertillon is credited as one of the first to have had to deal with the overwhelmingly unique problem of high photographic volumes, plates and negatives. (ref. Sekula, op.cit: pg 19.)
architect of the quantitative paradigmatic foundations of sociology; and Francis Galton, founder of Eugenics and the inventor of ‘composite portraiture’.253

The camera provided all three scientists the tool to espouse their own formula for reinforcing positivist paradigmatic definitions of the pathological demographics of the social deviant. Through these combined methods, the ‘criminal body’ became defined as a more extensive social body and a formalised concept of Western judicial polity. In summary, Sekula makes the point:

It is important to note the camera is integrated into a larger ensemble: a bureaucratic-clerical-statistical system of “intelligence”; this system can be

253 Ibid, pg. 56. Sekular comments that the absence from histories of photography, might possibly have been due to bourgeois scholarship concealment of the sinister machinations of modernisation.
described as a sophisticated form of the archive; the central artefact of this system is not the camera but the filing cabinet (295)(p.16).

Photographs were used by charitable organizations and philanthropic institutions to promote and raise public awareness about social housing, poverty, homelessness and unemployment, at home and abroad. Barnados charities for orphaned children placed the picture with the child’s physical traits and skills on cards for potential employers and foster parents. It was a response to the destitution of the urban slums of Leeds (296). Ironically, the same photographs were used for identifying absconders and runaways to State authorities.

4.31D Photographers, magazines, postcards, movies, military in the Pacific

Armed with cameras and film, the presence of colonial portraiture photographers emerged throughout the Pacific and by 1890 some 60 photographers many of Chinese and Japanese ancestry, were working in the Pacific Islands, with at least twenty based in Honolulu (292).

In peace time, global demand for illustrated magazines about the Pacific ran high. The burgeoning partnerships between universities, museums and commercial film companies like Harvard & Pathe gained prominence by the 1920s (275). New advances in half-tone process for reproducing photographs directly onto the same paper used for printed text, coupled with mass produced hand-held cameras like the...
Eastman Kodak 16 mm, allowed professional and amateur photographers to meet the veracious demands of Western audiences for illustrated magazines.

New Zealand photographers such as Alfred Tattersall and Thomas Andrew had shifted abroad to Samoa to further expand their substantial tourist photographic Pacific postcard collections (187, 283, 285). As well, there were a number of Australian photographers who were prolific in the publishing of visual images of Pacific peoples, particularly of Papua New Guinea during the 1920s.

Disagreement varies amongst post-colonial scholars about how colonial still photographs should be interpreted and viewed. While generally there is agreement that the repetitive theme of the impact of Westernisation on Samoan people is clearly present, what is less known is the degree of negotiation that may have existed between the European photographer and the individuals and groups that were the subjects of the photographs.

Maxwell for example contends that Thomas Andrew’s ability to forge close relationships with Samoans drew both admiration and respect for his work as a photographer. He is also viewed as having “lacked motivation to exploit” his photo subjects; and that the theatrically composed Greek-like portraits that he made of Samoans was to highlight them as “morally honourable”; rather than the derogatory poses that some of his other contemporaries such as Davis and Tattersall were doing of distasteful sexualised feminine images for tourist markets (Maxwell, p. 177) (283). Maxwell suggests after detailed examination of historical textual journals, it is possible that the relationship between colonised women and the western photographer was not always an exploitative one (p. 144).

Major serial magazines and serial encyclopedias such as The World of Today, The New World, Peoples of all Nations, Asia, National Geographic Magazine and Walkabout (285) featured pictures of Pacific peoples at home providing unprecedented visual education about the Pacific region. Photographs of Papua New Guinean people for example flooded the Australian markets with conservative sales figures reaching between 110,000 to 220,000 in the early twentieth century (286).
With high demand for images of Pacific families in their “native surroundings” the circulation and re-circulation of images, often with confused chronological indexing, was common practice in the popular press. Pacific and Samoan people were repetitively shown as subjects of a “progressive colonial regime” and “not” as partially-clothed exotics frozen in archaic and unchanging mythic pasts (p. 210) ((285) (p. 216)). The implicit contrast was with the commercial progress made by colonial states like Australia and New Zealand in the Pacific Islands.

Within the postcard manufacturing business, Pacific images produced from the 1880s were often recirculated 20 years later producing what Desmond calls this the “decontemporizing effect”, thus promoting the stereotypical binary forms of “civilized” and “native savage” (292)(p. 471). Teaiwa has argued of Paul Gauguin’s (1848-1903) painted still image of “wahine”, as a continuation where the appropriation and the privileging of the ‘embodied one’ represents the “whole of the Pacific” (288). Many images represented the sexual commodification of women’s bodies (featuring bare-breasted women) and stimulated simultaneous discourses between pornographic, educational and commercial/tourist industries.

A powerful and influential perspective that held sway up to the 1930s was the European linear preoccupation of convincing the world that the noble savage would ‘eventually die out’ in the face of the ‘superior metal of western modernity’. As biologically inferior, and with customs which lacked complexity or sophistication, Pacific natives required protection from the forces of white Western industrial capitalism to enable their survival into the future. Eurocentric lenses of Pacific peoples’ responses to industrial capitalism continued to be depicted in relative terms of “success or failure” (27), a key theme of many film plots to evolve from the Hollywood cinemas.

Ethnographic ‘moving film’ evolved as a genre of documentary film and a specialised branch of photography in the years preceding the First World War. By the mid-1920s three film genres in the representation of the “other” had become entrenched within Western societies educational and entertainment milieu: anthropological, fictional romance, and the documentary (289). Film titles and sub-titles were often formulaically designed:
They have typical members. We do not. They are unusual, but can be comprehended. We are usual, but ultimately incomprehensible. They are somewhat like us. We are not like us. They must be represented in the simplest way. We must be represented with subtle complexity (289).

The raft of Hollywood South Seas movies through the 1920’s constructed plots and storylines packed with anticolonial themes about Western immoral corruption upon Pacific islanders, whilst simultaneously warning against the inherent dangers of ‘turning native’ when Western travelers’ ventured too far from “civilisation” (279). Warnings against miscegenation (mixing of races) created by the tourism trade and immigration settlement patterns in America, were suffused with haunting terrors of identity loss and misplacement when white men fall to the so-called seductions of the Pacific paradisiacal beaches.

Photo A5.3 First photograph of person climbing coconut tree. (289)

What are less known are the technological advancements in film making which are associated with Samoa that were part of the Hollywood movie making. A raft of South Seas island films from the 1920s provided the first moving film footage depicting scenes of Pacific peoples in their Pacific homelands engaged in everyday life activities. American Hollywood film maker Robert Flaherty’s fictional romance
Moana: A Romance of the Golden Age (1926) portrays the protagonist Ta’avale (being paid and then filmed) to undergo a Samoan tatau (tattoo). Life as it might be seen every day (in Safune, Savai’i, the film’s location) contain scenes of Samoan men and women harvesting taro, fishing, hunting wild boar and the complex process of tapa cloth (siapo) production from the mulberry bark. Even more significantly, are the cinematic landmarks associated with this movie. Several critical firsts for technological innovation that became industry standard for Hollywood cinematography positions Samoans at the very centre: the first “boy-climbs-coconut-tree” (Photo A.4 Weinbereger Camera People) scene, long telephoto lenses were invented; the movie “narration” unique in ethnographic films delivered in a nervous, unnaturally rapid speech to give edgy dramatic tension (289); and a new “panchromatic film” that resulted in excellent skin tones in black and white produced for the first time from a camera invention created by Flaherty (275). The documented scenes of Samoan people in fairly ‘natural’ settings were considered unique for its period, because it had not previously been seen in the West (289). Yet these scenes were not dissimilar to the still photography widely circulated previously about Samoans in various publications, studio images posed and staged for eyes beyond the Pacific.
Lastly, the Catholic and Protestant mission posts that settled in the Pacific came equipped with modern cameras, cataloguing thousands of images. Millions of photographs are held in mission archives around the world (297). These became official ‘visual’ records to parent institutions about their missionary work and the conversions to Christianity. The Australian Methodist missionary Reverend George Brown can be criticised because of his anthropological formulaic captions and clinically static poses that typify the ethnographical scientific drawing of peoples as ‘racial types’. He shot 900 photographs of Pacific people between 1876 to 1903; 300 were produced in Samoa (273, 278). Ahren’s analysis highlights competing desires in Brown’s work (273). Firstly, the desire to show that Samoans under the Christian doctrine be viewed as, “equal in the sight of God”. Secondly, to show the inherent justification for the evangelical Christian missions in the Pacific to convert the ‘natives’ to ‘civilised’ status (273) (p. 191).

The armed forces were also a major source for photographic images of the Pacific region and its peoples. In Samoa during 1943 to 1945 there were between 25,000 to 30,000 troops (mostly American); with an estimated 62,000 allied military forces across the entire Pacific region (298). Foreign photographic studios followed war fleets into Pacific nations on extensive military surveillance and activities of the First and Second World Wars. Nearly two million negatives are housed at the Imperial
War Museum in London archives taken by military photographers from these activities and about 500,000 negatives by U.S. Army Signal Corps photographers were sent back to Washington, D.C. (299). Photographic records such as those taken by British Royal Navy Captain Acland in 1883, portray significant events which survives today in pictorial form. One such event is an historical reconciliatory meeting between opposing political groups led by Samoan Chief Mauga Lei (Tamasese alliance) and Chief Mauga Manuma (Malietoa Leaupepa alliance). On board of the quarter deck of the HMS Miranda a new metaphor illuminates the military ship as a space of containment in its “creative and provocative” form, rather than merely the “containment” of historical meaning (280, 300).

Histories of military or paramilitary activities which recruited “native warriors” in the Pacific peripheries abound in discourses about the unofficial, private and public images. In this context, the Polynesian body was modelled and defined according to various colonial formulas; some to advance various technological advancements associated with industrial expansion; others related to regulation through educational curricula (301), the arts (168) and military-tourist agendas (288).
4.3.1E The visual and textual in fieldwork

Pink presents a useful historical analysis of the way mainstream scholarly disciplines, particularly anthropology, dealt with photographic methodologies (193). Primarily, however, there were two other main objections. The first objection was the utilisation of the camera as an instrument of industrial capitalism, particularly for the pursuit of commercial and political agendas. The second was the rejection of any methodology that threatened the ‘intellectual’ integrity of the ‘real sciences’, and as mentioned earlier, threatened ‘preservation’ of for example, the Pacific cultures that faced ‘extinction’ at the hand of modern industrialisation.

Despite the prolific use of photography for their own field exhibitions, the founding patriarchal anthropologists such as Boas, Malinowski, Radcliffe-Brown and Mauss
upheld these views. Only since the 1950s, have these views changed within the field of social sciences.

4.3.1F The Social Scientists

As the philosophical debates about ‘textual’ scholarly works continued, the works of other German scholars like Wagner, Nietzsche and Heidegger, culminated in an interest and pursuit in the “truths of interpretation,” rather than the “methods of observation” (197, 302).

Between the 1930s and 1950s, particularly through the influential work of anthropologists like Margaret Mead and John Collier, the emphasis was on reconstruction of “sensory experiences” in fieldwork. The importance of visual methodology for the understanding and interpretation of culture and nationalism, in the application of the social sciences to ‘real problems’; distinguished those on the “applied” side of sociological sciences from those in the “pure/mainstream” (192).

It was Mead’s series of photographic exhibitions in Bali with her husband Bateson in 1936 and 1938 that championed the importance of visual materials for the accuracy of analysis and objectivity of field-work data. With a collection of 25,000 still photographs and about 2200 feet of 16-mm film, what started as a funded medical investigation on the etiology of schizophrenia about Dementia Praecox, generated an unparalleled push to the popularisation of the 16mm educational ‘documentary’ film, academic lecture series, monographs and articles around the world to audiences of the museum and university sectors for decades to follow (275).

Pink also argued that the notion of the importance of “reflexivity” and the “insider” perspective that abounds in the literature in contemporary social sciences, has not always existed (192). The camera was used by most anthropologists as a “passive and objective recording device”, premised on the basic assumption that it “did not distort the flow of social action but recorded directly, spontaneous social reality, unrehearsed, within the total natural setting” (303).

What perhaps is less known are the photographic series that Mead developed in her earlier work with the Kodak Brownie camera in Samoa, when she was aged in her
early 20s. Mead’s controversial book, “Coming of Age” has generated heated debate about whether it is a continuation of western intellectual negation of Samoan culture. A recent critique of the series of pictures that Mead made of a young woman called Fa’amotu was to ‘conceal’ the anonymity of the 68 young Samoan women that she interviewed from three villages of the Eastern Samoa archipelago; as well as attempting to depict Samoans as “people distinctly different from Americans, in their disproportionate presence and size” (280). Rightly or wrongly, Mead’s use of one person as a visual representation in her fieldwork highlighted some of the attempts to resolve research issues. Even less unknown was that Mead had in her interviews also used still photographs from a popular Hollywood movie about a Tahitian family, images similar to the children’s village life to elicit responses from young Samoan children (275).

4.3.1G History of the Photograph Album

As an instrument initially utilised and dominated by the ruling European classes, the camera eventually became a mass-produced commodity that could be purchased by the masses for their own consumption. The amassing of information at the core of the Enlightenment was based on the ‘passionate’ (281) and ‘obsessive’ (277) tendencies of the Victorian upper classes to collect and categorise things, new and old, odd and exotic from across every corner of the globe. With the establishment of the commercial photographic industry in the 1860s, family photographic albums also became popular, having evolved from an earlier format known as the “sentimental album” another carryover from the Western upper-classes that proliferated over a span of 30 years during the 1820s to 1850s (281). The rapidly increasing distribution of the camera and popularisation of the family album marked a significant shift in the West of the written text alongside illustrations (sentimental album), to visual representations and became universally accepted mediums for people of the Victorian and Industrial period across all social classes to express themselves pictorially.

Only more recently, has ‘visual’ diaries for data collection expanded in the health literature, since the philosophical debates within the fields of anthropology and sociology that started in the 1930s and 1950s through the influential work of scholars like Margaret Mead and John Collier, began to challenge the long held notion that
photographs were useful only as ‘illustrative appendages’ to fieldwork and could never supercede the primary importance placed on *textual interpretation*. As anthropologist Jay states these shifts across academic disciplines were: “…a renewed respect for the ear over the eye as the organ of greatest value” (302). Photographic methodologies could not be deemed ‘authentic’ or ‘valid’ if it was not dominated by ‘direct observation’ (visual) in the field and not conceived intellectually through ‘textual’ scholarly writings. Without long-term, on-location fieldwork observation (traditionally participant observation) the study of cultures and societies lacked both the rigor and efficacy that was required in scientific enquiry (p.7) (192). Applied anthropologists counter-argued that ‘culture’ needed to be understood through the interdisciplinary study of visual materials, including film and popular fine art, literary media and performance genres (192) (p. 10).

4.3.1H Health diaries and photographs

Advancing on the multi-disciplinary approaches which draws together textual and visual disciplines, the use of photography within research methodologies has certainly expanded within and across the field of qualitative medical and public health discourses, as attested by the literature review of Photomethods (above).

‘Prospective diaries’ when used alongside photographs, not only produces rich research data, but can greatly assist patients’ and their families within clinical settings such as intensive care units, to understand the events of critical illness, formulate more realistic goals for recovery and as a source of comfort from a bereavement (304).

The ‘written diary’, ‘journal’, or ‘log book’ are used extensively for nursing and clinical practice studies as a major format of recording patients’ symptoms, medical responses and activities (305). Also known as the ‘health diary’ the data which was similar to information collected through the participant’s interview was a “helpful outlet”, for patients to talk about their experiences of cancer (306).

Visual studies which used a range of methods such as pencil drawings (307), spider maps and disposable cameras both highlighted that data produced from the photographs helped to deepen the understanding about the social phenomena being
examined particularly within ethnic communities (Peruvian Amazon and Kampala street children)

4.3.1 Summary

The history of the camera has been part of Samoan society from the beginning. The western paradigms that laid the foundation of western science and criminology has been part of the camera’s genesis from the time it was invented. As the images of Pacific people and their nations were propagated around the world, the academic, scientific and artistic communities developed their respective narratives around the ‘native’. With the mass popularisation of the camera and photographic album, families in industrial cities began producing their own pictorial images that was once dominated by colonial photographers. From the 1960s onwards, the academic disciplines reinvigorated the importance of the photograph. However, because of the philosophical divisions about the way that real life events and cultures should be interpreted, it would take almost another half century before visual images would gain consistent recognition as a credible methodological approach within the social sciences.
Appendix 4.4 Photovoice Process

Goals (Source: Website www.photovoice.org)

PhotoVoice has three main goals:
- to enable people to record and reflect their community's strengths and concerns;
- to promote critical dialogue and knowledge about personal and community issues through large and small group discussions of photographs; and
- to reach policy makers.

Photo Voice is highly flexible and can be adapted to specific participatory goals (such as needs assessment, asset mapping, and evaluation), different groups and communities, and distinct policy and public health issues.

Stages
The stages of Photovoice include:
1. conceptualizing the problem; defining broader goals and objectives
2. recruiting policy makers as the audience for PhotoVoice findings
3. conducting Photo Voice training; training the trainers
4. devising the initial theme/s for taking pictures
5. taking pictures
6. facilitating group discussion: critical reflection and dialogue
   - selecting photographs for discussion
   - contextualizing and storytelling
   - codifying issues, themes, and theories; documenting the stories
7. conducting the formative evaluation
8. reaching policy makers, donors, media, researchers, and others who may be mobilized to create change; conducting participatory evaluation of policy and program implementation

Community training and process (Source: Website www.photovoice.org)
The first PhotoVoice training begins with a discussion of cameras, ethics, and power; ways of seeing photographs; and a philosophy of giving photographs back to
Community members as a way of expression appreciation, respect, or camaraderie. The curriculum may then move to address mechanical aspects of camera use.

Community people using PhotoVoice engage in a three-stage process that provides the foundation for analysing the pictures they have taken:

1. Selecting – choosing those photographs that most accurately reflect the community’s concerns and assets.
   The participatory approach dictates this first stage. So that people can lead the discussion, it is they who choose the photographs. They select photographs they considered most significant, or simply like best, from each roll of film they had taken.

2. Contextualizing – telling stories about what the photographs mean
   The participatory approach also generates the second stage, contextualizing or storytelling. This occurs in the process of group discussion, suggested by the acronym VOICE, voicing our individual and collective experience. Photographs alone, considered outside the context of their own voices and stories, and would contradict the essence of PhotoVoice. People describe the meaning of their images in small and large group discussions.

3. Codifying – identifying the issues, themes, or theories that emerge
   The participatory approach gives multiple meanings to singular images and thus frames the third stage, codifying. In this stage, participants may identify three types of dimensions that arise from the dialogue process: issues, themes, or theories.
   They may codify issues when the concerns targeted for action are pragmatic, immediate, and tangible. This is the most direct application of the analysis. They may also codify themes and patterns, or develop theories that are grounded in data that have been systematically gathered and analysed in collective discussion.

Conclusion

PhotoVoice turns on involving people in defining issues. Such an approach avoids the distortion of fitting data into a predetermined paradigm; through it we hear and understand how people make meaning themselves, or construct what matters to them. PhotoVoice...is not simply the shuffling of information around, but entails people reflecting on their own community portraits and voices and on what questions
can be linked into more general constructs or can be seen to be interrelated. It is a method that enables people to define for themselves and others, including policy makers, what is worth remembering and what needs to be changed.
Appendix 4.5 The Visual Diary (Self-produced by Ramona)

4.5.1 Exploring and implementing a Photo Diary for the study

A close friend and colleague had recently completed a Master’s thesis using Photovoice. Based on her first-hand experience, she suggested the idea of a Visual Diary, “…participants responded more easily to the task of taking photographs when they were given examples to view,” (Karilyn Andrew, personal communication). In light of this, I produced a Visual Diary to introduce the research issues to the participants (see Appendix 4.5.1). However, I thought that it might be worthwhile testing the notion of whether ‘producing’ and ‘viewing’ photographs were in themselves considered to be beneficial to Samoan families.

As an exercise to understand and consciously think about the camera production process I spent at least a week taking photos with a disposable camera on the general theme of ‘home’. I also included photos of important places such as my nephew’s school, landscape shots of an inner-city suburb where I grew up, tree tops, the cemetery where my father is buried and interesting cultural household objects (Samoan kava bowl, orator’s staff); places and objects that might express aspects of Samoan identity and family life. I also made a special visit to the hospital renal unit, taking photos of signage and dialysis arm chair. (The Visual Diary for the Study Appendix 4.5).

Throughout the process, I tried to imagine how a participant of my study might go about making their own photos and kept in mind the potential difficulties for them. After developing the film at a local supplier I displayed them in a photo album to consider practical storage and aesthetic factors; presenting the photos to help the participants talk easily about their experiences.

In July 2006 while conducting my field work I showed my visual diary to four key informants in my home detention study (Pacific prison officers) to see how they would respond. Not only were their unanimous responses overwhelmingly positive, they could see the rationale of using images to illicit participants’ stories for the study. It also helped them more easily ‘picture’ life at home for a home detainee and differences between institutional prison life and imprisonment at home; the push and

pull factors of reoffending; the realities impacting on Samoan families. Their feedback gave me confidence of using a visual diary as an explanatory and instructional tool in the study’s methodology and how it could be used effectively with the participants. While I did consider that my visual diary might unduly influence the participants ideas about what, why and how they might produce their photographs it was critically important to have an communication approach that could describe simply, the significant purposes and aspects of the study; and to do so within the short time available of a first meeting so that the participants were fully aware of the demands and requirements of the study.

Photo A4.5.2 Visual Diary – Information about the Study
Appendix 6.2 Methods of recruitment home dialysis

Recruitment Approach 1 – Pamphlet distributed by renal staff at the hospital renal unit

Dialysis participants were recruited by snowball sampling from the researcher’s community network. A first approach however was made to the Renal Unit to a senior member of the staff who agreed to help with the study. It was suggested that a simpler outline of the Information Sheet be designed as a pamphlet for distribution to patients in the Renal Ward. Fears that the staff might be seen to be “pressuring patients” into participating in the study were made clear to me at the outset by an advisory member, who agreed to pass on the pamphlet to staff. As a result, staff was encouraged not to actively promote the study and to only approach patients who ‘might potentially’ be interested. It is unknown how many pamphlets were distributed or how many patients were approached; none the less there were no participants recruited from this method (Fig. A6.1)
Appendix 6.3 Methods of recruitment home dialysis snowball

Recruitment Approach 2 – Community network & snowball technique

Given the ‘no uptake’ of participants from the first recruitment method, I made a direct approach through my own networks of family and friends in the community. The first two families I approached snowballed to other families who had been through the dialysis unit. In total five families (12 individuals) were recruited through this method.
Appendix 6.4 Methods of recruitment home detention

Home Detention Study

Stage One involved gaining permission from the relevant state organisations as a researcher to enter and interview participants at a New Zealand prison.

Home Detention Recruitment & Interviews

Detainee recruitment and interview process

I was required to work closely with the Receiving Officer (RO)\textsuperscript{255} while conducting the study at the prison. The RO is a staff member at the prison authorised to screen potential participants (detainees) that I could interview. As illustrated above in Fig.

\textsuperscript{255} The RO holds authorisation to admit and release all prisoners from the institution, and assigns prisoners according to sentencing status to their allotted prison cells.
recruitment and interview, processes for the home detention study involved two main stages.

The first stage involved the RO contacting me by email that there was a prisoner had indicated interest in the study and had signed a consent form agreeing to an initial meeting to introduce myself and to explain what the study was about. At the meeting I sought agreement from the prisoner to photograph their cell and a date to carry out the first main interview. Over April to December 2006 at least eight potential home detention prisoners were identified, however only three matched the participant criteria.

**Stage 1 Participant Interview at the State Prison**

1. The Receiving Officer (RO) screened and identified a potential participant (detainee) from within the general prison population and provided with a Detainee Information Sheet and Consent to Contact Form. If the participant agreed to be involved in the study she signed the CCF and passed it back to the RO who then contacted me for an authorised visit to meet the participant.

2. At the first visit with the potential participant, I described what the study was about, showed her the Visual Diary and explained that the study involved taking photographs of her experiences of prison and home detention. At this meeting I also explored whether the participant was willing to use a disposable camera to take photos of their cell. If they agreed, a prison officer would escort the two of us to the participant’s cell and remained in close proximity while the photographs were taken. After the photos were taken, we returned to the interview room to resumed interviewing the participant about their experiences of prison, their first night and what they expected to achieve when they left prison to carry out home detention sentencing at home. At this stage I also explored the likelihood of the participant’s sponsor (normally spouse, parent or family member) being willing to participate in the study. I also gained permission from the participant to be able to contact them for the second stage interview.

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256 The second interview for all three participants was not necessary because the detainee agreed at the first meeting to be interviewed.

257 Samoan home detainees were located outside of the Wellington central region in Auckland and Christchurch. Others had already completed their home detention and were no longer under the jurisdiction of the NZ Prison Service.
of the study. This meant I had to acquire the participant’s home detention address and telephone number.258

3. After the interview, I collected a signed Participant Consent Form from the participant and left a Sponsor Information sheet to pass onto their sponsor.

Stage 2 Participant Interview/s at Home during Home Detention

When a prisoner is released into the community, they are placed under the jurisdiction of the Community Probation Services (CPS) and subsequently monitored by electronic surveillance with random visits made by security agents.

1. In preparation for the second meeting, I made contact with the participant at the address that they provided. Had I not been able to reach them I planned to contact the local Community Probation Service in the closest known address that the participant gave. Over the phone or in-person, I asked the participant what their preferred method of receiving a disposable camera (by Visit 2 or courier post) and also ascertained the Sponsor’s interest in the study.

2. Having agreed for me to ‘hand-over’ the camera by courier post or hand delivery, I set a date where the used disposable camera could picked-up or ‘sent back’ by courier.

3. Interview 2: Having received the participant’s used camera, the film was delivered and developed.

4. At the next step, I ensured I had a date booked with the participant and the sponsor to interview them by audio-tape about their photographs and experiences of home detention.

5. After the interview, I asked the participant and sponsor to complete the relevant consent form and asked them to indicate on the form whether they wanted a summary of the findings of Home Detention Study to be sent to them and whether they had any recommendations to be passed onto the NZPS and Ministry of Justice, Corrections Department. Comments collected with view of future action of recommendations.

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258 At this stage of the fieldwork there was nothing to indicate that the information provided by the detainee was incorrect. Also, there were two options of being able to find the detainee’s validated address through the prison or correctional probationary services.
Appendix 6.5 Participant Inclusion and exclusion criteria for both studies

Home Dialysis Participants

Inclusion Criteria

The inclusion criteria for the participants of the dialysis case study to reflect the public health services which patients and their carers were enrolled or registered:

Case Study Group 1

Dialysis Patient

a person in receipt of specialist hospital care in the form of renal replacement therapy (RRT); currently/previously undergoing haemodialysis or peritoneal dialysis treatment in their home or satellite/hospital dialysis unit;

- has received RRT at least 3 months prior to interview;
- a person of Samoan ethnicity;
- aged at least 16 years old with no upper age limit.

I. Dialysis Carer

- a person responsible for the on-going daily physical, emotional, spiritual or financial support to a dialysis patient;
- aged at least 18 years old with no upper age limit.

II. Key Informant

- persons with special skills and competency for the provision of health and/or social services;
- can include hospital social workers, occupational therapists, nurses, general practitioners, prison officers, solicitors, advocates, renal physicians and community health workers.

Field Visits and Safety Dialysis

Appointments for interviews were organised to fit the availability of the participants. On three occasions, while being interviewed, dialysis participants expressed physical and emotional discomfort. On these occasions, I showed flexibility and offered to close the interview and rescheduled for another day when the participant might feel better to be interviewed. I occasionally notified the Secretary about dialysis home

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259Haemodialysis: treatment for kidney failure in which the blood passes through an artificial dialyser to remove wastes and water. Peritoneal dialysis: treatment for kidney failure in which dialysis fluid is introduced into the peritoneal cavity to remove wastes and water from the blood. There are two types: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Automated Peritoneal Dialysis (APD) (Reference: Living with Kidney Failure, Published by the New Zealand Kidney Foundation, 2004, pg. 73 and 74.)
visits, however, given that the participants were known more to the researcher, there was less concern compared to the detainees.

Home detention Participant
Inclusion Criteria

The inclusion criteria described below is written for the participants of the home detention case study group and reflects the language and terminology of the New Zealand prisons and correctional services where the participants were involved:

I. Detainee

- a Samoan person detained and sentenced under the jurisdiction of a New Zealand Prison may include;
- a person serving home detention on ‘front-end’ (at the beginning of a two years or less sentence); or
- ‘back-end’ (at the end of a sentence period lasting more than two years as a release condition);
- anyone who has completed home detention;
- Aged at least years 16 old with no upper age limit.

II. Home Detention Sponsor

- Is a person who is validated and certified as the ‘sponsor’ by the Community Probation Service, Department of Corrections;
- responsible for a detainee over the duration of the sentencing period of home detention;
- involved in the on-going daily physical, emotional, spiritual or financial support of the detainee;
- Aged at least 18 years old with no upper age limit.

III. Key Informant

- Includes prison officers and justice sector personnel with experiences of home detention or working with home detainees.
Appendix 6.6 Summary of Information Sheets and Consent Forms

<table>
<thead>
<tr>
<th>Participant</th>
<th>Form Type</th>
<th>Form Identification Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home Dialysis (Case Study 1)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialysis patient</td>
<td>Consent to contact</td>
<td>2.dy.i</td>
</tr>
<tr>
<td>Dialysis patient</td>
<td>Information sheet</td>
<td>2.dy.ii</td>
</tr>
<tr>
<td>Dialysis patient</td>
<td>Consent to participate</td>
<td>2.dy.iii</td>
</tr>
<tr>
<td>Dialysis patient</td>
<td>Consent to photograph</td>
<td>2.dy.iv</td>
</tr>
<tr>
<td>Carer</td>
<td>Information sheet</td>
<td>2.c.ii</td>
</tr>
<tr>
<td>Carer</td>
<td>Consent to contact</td>
<td>2.c.iii</td>
</tr>
<tr>
<td>Carer</td>
<td>Consent to photograph</td>
<td>2.c.iv</td>
</tr>
<tr>
<td><strong>Home Detention (Case Study 2)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detainee</td>
<td>Consent to contact</td>
<td>1.dt.i</td>
</tr>
<tr>
<td>Detainee</td>
<td>Information sheet</td>
<td>1.dt.ii</td>
</tr>
<tr>
<td>Detainee</td>
<td>Consent to participate</td>
<td>1.dt.iii</td>
</tr>
<tr>
<td>Detainee</td>
<td>Consent to photograph</td>
<td>1.dt.iv</td>
</tr>
<tr>
<td>Sponsor</td>
<td>Information sheet</td>
<td>1.s.ii</td>
</tr>
<tr>
<td>Sponsor</td>
<td>Consent to participate</td>
<td>1.s.iii</td>
</tr>
<tr>
<td>Sponsor</td>
<td>Consent to photograph</td>
<td>1.s.iv</td>
</tr>
</tbody>
</table>

**SUMMARY DESCRIPTIONS**

*Consent to Contact Form (CTC) for Patients/Detainees*
- distributed to potential participants by agency personnel on respective public institutions (Prison/Renal Ward) on behalf of the researcher;
- Confirms consent for the agency to notify the researcher that the participant is interested in the study and may be contacted.

*Information Sheet (IS) for Carers (dialysis)/Sponsors (detention)*
- outlines the core components of the study (goals and objectives);
- describes the stages involved in collecting information in relation to their experiences of living with RRT/home dialysis
- processes of using cameras and photographs to record their experiences;
- key contact details of the researcher and academic supervisors;
- a Statement confirming the study has Ethical approval from the University;
- A statement that participants can withdraw from the study.

*Participant Consent Form (PCF) for all Participants*
- Signed consent and agreement to participate in the study;
- Agreement/Disagreement to have a copy of the findings sent to them at the completion of the study;
- Consent for participant’s data to be used for the purposes of academic publications, doctoral thesis and other academic publications, professional journals and conferences.

*Guideline to Take Photo Sheet (GTP) (families only)*
- instruction on how to use and take care of the disposable camera
- ideas about what photos to take process about how the researcher will collect the camera and return the photographs to participant
Invitation to Participate in the ‘Home Dialysis Study’

Project Title: Family-Centred Healing At Home.

Malo le Soifua,
I am a Samoan student at the University of Otago. I am interested to learn about the experiences for Samoan people on home dialysis, and also to talk about other topics like Samoa, health, fofo Samoa and the fa’a Samoa. If you have some time, I would really appreciate coming to talk to you about my study. I can come to your house and meet with you on a day that is best for you. If this is something that you think would be of interest, then please ring me directly on the following number: 04 3855-999 extension 4897

“O lenei Su’esu’ega ua fa’amaonia mai lea e le Univesite o Otago Komiti o le Human Ethics.”

Manuia la’asaga ole aso.

Ole Valaulia I le Auai I le Su’esu’ega I le Fa’amāmā Toto

Ulutala O Su’esu’ega: Faatāuaina ole Fa’amatolōga ile Si’osi’omaga ole Aiga (Fa’amāmāina ole Toto)

O a’u o se tama’i ta’i aoga ile Otago Univesite. Ou te fiafia lava e iloaina ia malamalamaga o tagata o lo’u atunu’u (Samoa), i le uiga ole fa’amāmā Toto. Ou te fia talatalanoa fo’i i isi mataupu fa’apei ole soifua maloloina, fofo Samoa, ma le aganu’u Samoa.

Oute fia talosaga atu pe mafai ona fa’aavanoa sou taimi ou te aluatu ai e talanoa ma oe e uiga i la’u saili’iliga. Oute matua fa’afetai tele lava. Fa’afeso’ota’i mai a’u i le telefoni ua tusia i lalo.

la Soifuaina,

Ramona Tiatia
PhD Research Fellow
He Kainga Oranga/Housing and Health
Wellington School of Medicine & Health Sciences
PO Box 7343
Wellington South
Email: ramona.tiatia@stonebow.otago.ac.nz

If you have any questions about my study you can also ring my supervisor:
Ass. Professor Philippa Howden Chapman 04 3855-999 extension 6047

“O lenei Su’esu’ega ua fa’amaonia mai lea e le Univesite o Otago Komiti o le Human Ethics.”

Manuia la’asaga ole aso.
Fa’amatalaga Mo Le Su’esu’ega Ole Fa’aogaina Ole Fa’amāmā Toto ile Aiga.
Appendix 7D.2 Information Sheet about Study for Dialysis Patient and Carer (English language)

Information About The ‘Home Dialysis Study’

**Project Title:** Family-Centred Healing At Home.
Information Sheet Dialysis Patient [2.dy.ii]

Talofa Lava,

I am a Samoan student at the University of Otago. In 1995 I undertook a study with Samoan traditional healers to find out their views about Samoan people’s health experiences in the Wellington region. As a continuation of that study, I am seeking to explore key issues related to the Samoan peoples’ experiences of ‘healing at home’ particularly in relation to hospital care (specifically dialysis care) in the home and family environment, because there is very little information of this kind in New Zealand.

I would like to meet with you over a period of three months. During this time, you will be given disposable cameras to document your daily life. Specifically, participation in this project will involve:

1. Three to four meetings lasting no longer than three hours in total. The first meeting will be to introduce myself as the researcher and describe the study. A questionnaire about the study will be provided.

2. The second meeting, which will be at your home of residence, will be to offer you and your carer/support person a camera each to document daily activities over a period of one month.

3. The third meeting is to talk about the photos and some of the areas of the study, which I would like to discuss in depth. The discussion at this session will be recorded on tape.

4. Reviewing transcripts of the interview as a means of checking that the information is accurate.

5. At the completion of the study, a gift and Summary Report of the Research Findings will be provided to you in acknowledgment of your time and participation. The gift is not a ‘reward or payment’, but a customary gesture of a mea alofa.

In the study, I would like to discuss with you a range of topics, such as, the health care you receive at home, what helps you the most in terms of dialysis, supports, aspects of fa’a Samoa (Samoan culture) and traditional healing (fofo Samoa) and the justice system in Aotearoa, New Zealand.

The benefits of participating in this research are to hopefully give participants an opportunity to share in a safe environment their experiences about the services they receive within their family environment and any improvements they believe could be made in the provision of health services for Samoan dialysis patients and their family. Secondly, the project will contribute to professional and public knowledge and understanding of the experience of healing at home Samoan families, about which currently no New Zealand research has been undertaken.
The University requires that ethics approval be obtained for research involving human participants. Participation is voluntary and participants are free to withdraw at any stage from the study. The information and any data obtained from the participants will be destroyed five years after the study is completed. You will retain ownership and copyright of all their photographs and negatives. The researcher will have no access to photographs and/or negatives without the additional written permission of participants. Participants will be required to maintain the confidentiality of the others in the study. Tape-recorded data will be transcribed by myself and written up in such a way that you will not be able to be identified. The only person aside from myself who will have access to the data will be my supervisor, Associate Professor Philippa Howden-Chapman and Dr. Sarah Dean. The material collected will be written up for a thesis to be submitted for examination and deposited in the University Library. Material may also be used in articles submitted for publication in academic or professional journals and for conference presentations.

Whilst all the information that is shared by the participant to the researcher is confidential, there will be only one situation where this may be not maintained. This would be a situation if the participant is seen to be in immanent or immediate potential danger to themselves or to another person. In which case, the research would need to notify the necessary emergency services or relevant health professionals.

If you have any other questions or would like to receive further information about the project, please contact me:

Ia Soifuaina

Ramona Tiatia
PhD Student
He Kainga Oranga/Housing and Health
Wellington School of Medicine & Health Sciences
PO Box 7343
Wellington South
Telephone: 04 3855-999 extension 4897
Email: ramona.tiatia@stonebow.otago.ac.nz

Or my Supervisor:
Professor Philippa Howden Chapman 04 3855-999 extension 6047

“This project has been reviewed and approved by the University of Otago Human Ethics Committee”.

Fa'afetai lava mo lou fesoasoani. Manuia la'asaga ole aso.
Fa’amatalaga mo le Su’esu’ega Ole Fa’aāogaina ole Fa’amāmā Toto Ilou Maota
Information Sheet Dialysis Patient [2.dy.ii.s(i)]

Talofa Lava

O au ole Samoa oute a’oga ile Univesite of Otago. I le tausaga 1995 sa ou faia ai se su’esu’ega e uiga i fofo Samoa, (taulasea) ma latou manatu po’o iloa e tau i soifuia maloloina o tagata Samoa i Uelinitone. Ole fa’aauauina o lenei su’esu’ega, oute fia saili atili ni so’otaga o tagata Samoa ma latou malamalama ile fa’amalōlō i latou aiga aemaise le so’otaga oē e fa’aaogaina ole fa’amāmā toto ile maota me le aiga auʻa ‘e le tele se malamalama ma ni fa’amatalaga olenei matāupu i Niu Sila.

Oute fia fesili atu sei ū fa’amatala lou malamalama ma ni ou manatu, o oe ose tagata olo’o fa’aaogaina lenei auaunaga, ole fa’aāogaina lea ole faamāmā toto ilou lava maota, fa’apei o le auaunaga ole soifua malōlōina ilou fale, o le tulaga olou fale feagai ai ma le gaoioiga ole fa’amāmāna ole toto, oute aganu’u fa’a Samoa (Samoan culture), olou malamalama ile fofo Samoa (traditional healing) ma le matāgaluega ole soifua maloloina i Aotearoa, Niu Sila.

O mea olo’o ta’ua i lalo ole’a fesiligia ai oe ilenei su’esu’ega:

1. O le’a e auai ini fonotaga se tolo po’o le fa ae le sili atu ile tolu itula le umi. Olenei fonotaga ole’a ou fa’ailoa atu lo’u nei tagata ma fa’amatala le uiga ole su’esu’ega. Oute fia fesili atu fo’i pe fa’atagaina a’u oute talanoa i lē o lo’o fesoasoani ia te oe ilou maota. Olenei tagata ‘e lelei fo’i pe’a fai o le tausia oe. Olenei fonotaga oute fa’amatala atu ia te oe, na’o oe po’o fa’atasi foi ma le fesoasoani ia oe le uiga olenei su’esu’ega. Olo’o iai se lisi olenei polokalame ma ni fesili mo le su’esu’ega e mafai ona avatu mo lou iloa. Afai ete finagalo malie ete auai ilenei su’esu’ega ona ou mana’omia lea o luo saini mo le fa’atagaina fa’atasi ai ma le faia ose iai taimi toe fono ai ta’ua.

2. Ole fonotaga lua ole ofaina atu lea ose mea pu’eata (fa’aaoagā ma tia’) mo oe ma lou fesoasoani ‘e pu’eina ai lou gaoioiga mo se masina. Oute fiafia e pu’eina au gaoioiga ini ata auʻa ‘e ese fo’i le matagofie le va’aiaga i ata ma faigofie i lo’o le tau sailiga oni upu ‘e fa’amatala ai lau gaoioiga ile tausiga olou gasegase.

3. Ole fono lona tolu, ole talanoaga lea e uiga i ata ma ni matāupu taua olenei su’esu’ega po’o ni matāupu foi ete fia talanoa atili ai e uiga ilenei su’esu’ega. Olea pu’eina foi lenei fonotaga ise lipine. Oute talatalanoa foi ia oe ma lau fesoasoani tai to’atasi. E mafia ona tatou talanoa fa’atasi pe a uma ona pu’eina le lua lipine tai to’atasi.

4. O le’a maua fo’i se avanoa e tu’uina atu pe ete fia fai fa’atauina ina tusitusiga olenei fa’atalanoaga, e avea fo’i ma se auala e fa’amaonia ai tusitusiga ua ou fa’amaunia.

Ole tāua olou auai ilenei su’esu’ega ole tu’uina atu lea ose avanoa e fa’atalatalanoa ina ai ni matāupu matagofie e uiga ole fa’aăogaina ole fa’amāmā toto ilou maota. Po’o le’a lava ni fa’amatalaga ma ni ili’iliga ea fa’aleleina atili ai tulaga o mo gasegase o le fa’amāmāina ole toto ma latou aiga i tonotonu o Niu Sila olea tu’uina atu lea ile matāgaluega ole malōlō soifulaina. Ole’a tusia fo’i ise auala e natia ai lē sa ou fa’atalanoaina.
O lona lua, o lenei saili'iliga ole'a lagolago tele mo tagata fa'igaluega ma le lautele ina ia malamalama ma silafia le tāua ole fa'amalolōga mo aiga Samoa iō latou lava maota, auā e leai se su'esu'ega fa'apea o faia i Niu Sila. O lenei su'esu'ega e avea ma se vaega ole fa'aiLOGA ole PhD lea oute faia i lalo ole ulutala “Fa'atāuaina ole Fa'amalolōga ile Si'osi'omaga o Aiga”.

O lo’u auai ilenei su'esu'ega i lo’u loto faitalia ma ‘e mafai ona fa'amuta lo’u auai i so’o se taimi. Oni fa’amatalagaga ma ni fa‘amaumauga mai ile ta talatalanoaga ole’a fa’aleaogaina ile lima taiaga mai le taimi ua uma ai lenei su'esu'ega. Ete u’umia le pule i ata uma ma latou kopī. Ole e ona lenei su'esu'ega, ole’a leai sona aiā i ata vagana ua iai seisī fa’atagaga mai le e ona ata. E mana’omia fo’i lou natia o se isi sa auai ilenei su’esu’ega. O talatalanoaga uma sa pu’eina o lea ou tusia ise auala po'o se gagana e natia ai lē sa tufa mai. O nisi vaega ole’a latou va’ai ilenei su’esu’ega o a’u faafautuaga, ole Polofesa So'otaga o Philippa Howden-Chapman ma Foma’i Sarah Dean. O galuega uma sa aofia ilenei su’esu’ega ole’a fa’amāpo’opo’opo ma tusia lea I se lipoti ona tu’u atu lea mo su’e ga, ona teuina lea ile fale tūsi ole univesite. O nisi fo’i vaega o nei su’esu’ega e mafai fo’i ona tu’u ina atu mo le fa’aiLOGA lautele i a’oa’oga maualuluga po’o le faia ai fo’i oni tufatufaga mo ni fonotaga.

O mātāupu uma lava sa tatou fetufa’ai ai e nanatia uma lava. Tasi lava le fa’atagaina ona ne'i iai se tulaga e lamatia ai lou tagata po’o seisī fo’i e afaina ai. Ole tiute lea olē sa faia le su’esu’ega e logo tagata e fetaui tonu ma le fa’afoia olea fa’afitaulī.

Afai ol'o iai ni fesili po’o le fia malamalama atili e uiga i lenei saili’iliga, fa’amolemoole vala’au mai po’o le fesili I lē sa tau a’aoina atu lenei tusi.

Ramona Tiatia  
PhD Student  
He Kainga Oranga/Housing and Health  
Wellington School of Medicine & Health Sciences  
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Wellington South  
Telephone: 04 3855-999 extension 4897  
Email: ramona.tiatia@stonebow.otago.ac.nz

Po’o lou pule:  
Professor Philippa Howden Chapman 04 3855-999 extension 6047

"O lenei Su’esu’ega ua fa’amaonia mai lea o le Univesite o Otago Komiti o le Human Ethics.  

Fa'afetai lava mo lou fesoasoani.  Manuia la’asaga ole aso."
Appendix 7D.4 Information Sheet about Home Dialysis Study for Dialysis Carer (Samoan Language)

Information Sheet Dialysis Carer  [2.c.ii.s(1)]

Talofa Lava (Dialysis Carer)

O au ole Samoa oute a'oga ile Univesite of Otago. I le tausaga 1995 sa ou faia ai se su’esu’euga e uiga i fofo Samoa, (taulasea) ma latou manatu po'oiiloa e tau i soifua maloloina o tagata Samoa i Uelinitonite. Ole fa'aaauauna i o lenei su’esu’euga, oute fia saili atili ni so'o'taga o tagata Samoa ma latou malamalama ile fa’amalololi i latou aiga aemaise le so'otaga o e fa’aaoogaina ole fa’amamah toto ile maota ma le aiga au ‘e le tele se malamalama ma ni fa’amatalaga olenei matâupu i Niu Sila.

Oute fia talanoa mo oe, pe’a fai o loo ‘e taisia se tasi olo'o fa’aaoogaina le fa’amamah toto ile aiga. Ole olo'o a'afia ilenei auuanauga, (olo'o fa’aąagoina le fa’amamah toto) ua malie ē auai ilenei su’esu’eega, ma ole’a latou fesili mo lou fa’atagaina o a’u ‘e talanoa ia oe. Oute mautinoa lau galuega ole tausi ma’i e tāua tele. Oute fiafia i ni ou manatu e uiga ilenei auuanauga mo le aiga ma sou iiloa mo lenei sa’iglia. Oute manatu lava ‘e tūtusa matâupu ole’a ou fesili ai fo’i ilē u a mai, fa’apei o le auuanauga ole soifua maloloina ilou fale, o le tulaga olou fale e feagai ai ma le gaoioiga ole fa’amamahaina ole toto, ole aganu’u fa’aSamo (Samoan culture), olou malamalama ile fofo Samoa (traditional healing) ma le matâgaluega ole soifua maloloina i Aotearoa, Niu Sila.

O mea olo’o ta’ua i lalo ole’a fesiliga ai oe ilenei su’esu’eega:

1. O le’a e auai ini fonotaga se tolu po’o le fa ae le sili atu ile tolu itula le umi. Olenei fonotaga ole’a ou fa’ailioa atu lo’u nei tagata ma fa’amatala le uiga ole su’esu’eega. Olenei fonotaga oute fa’amatala atu ia te oe, na’o oe po’o fa’atasi fo’i ma o ē fa’aaoogaina ole fa’amamah toto ile maota. Olo’o iai se lisi olenei polokalame ma ni fesili mo le su’esu’eega e mafai ona avatu mo lou iilo. Afa’i ete finagalo malie ete auai ilenei su’esu’eega ona ou mana’omia lea o lau saini mo le fa’atagaina fa’atasi ai ma le faia ose isi taimi toe fono ai ta’ua.

2. Ole fonotaga lua ole ofainia atu lea ose mea pu’eata (fa’aąagō ma tai’a) mo oe ‘e pu’eina ai au gaoioiga e faia mo tausiga, tusa po’o se masina le umi olea galuega. Oute fiafia e pu’eina au gaoioiga ini ata au’a ē ese fo’i le matagofie le va’aiaga i ata ma faigofie onafai ai se lipoti i lo’o le tau sailigia oni upu ‘e fa’amatala ai lau gaoioiga ile tausiga oē olo’o fa’aaoogaina ole faamamah toto. E faitalia lava oe po’o ē ata ete pu’eina ae oute fa’asino atu le fomu e tatau ona sainia ese tagata olo’o i totonu ose ata tatou te fa’aogaina ilenei su’esu’eega.

3. Ole fono lona tolu, ole talanoaga lea e uiga i ata ma ni matâupu tāua olenei su’esu’eega po’o ni matâupu fo’i ēte fia talanoa atili ai e uiga ilenei su’esu’eega. Ole’a pu’eina fo’i lenei fonotaga ise lipine. Oute tatalanoa fo’i ia oe ma tai to’atasi. E mafai ona tatou talanoa fa’atasi ma le tagata ma’i, pe’a uma ona pu’eina le lipine.

O le’a maua fo’i se avanoa e tu’uina atu pe ete fia faiata ina tusitusiga olenei fa’atalanoaga, e avea fo’i ma se auala e fa’amaonia ai tusitusiga ua ou fa’amauina.

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Ole tāua olou auai ilenei su’esu’ega ole tu’uina atu lea ose avanoa e fa’atalatalanoa ina ai ni matāupu matagofie e uiga tama’ita’i tausi ma’i mo lē e fa’aaogaina le fa’amāmā toto. Po’o le’a lava ni fa’amatalaga ma ni ili’iliiga e fa’aleleina atili ai tulaga o mo Gasegase Mo le Fa’amāmāina ole Toto ma latou aiga i totonu o Niu Sila olea tu’uina atu lea ile matāgaluega ole soifua malōlōina. Ole’a tusia fo’i ise auala e natia ai lē sa ou fa’atalanoaina.

Olona lua, o lenei saili’iligia ole’a lagolago tele mo tagata faigaluega ma le lautele ina ia malamalama ma silafia le fa’amalōlōga mo aiga Samoa iō latou lava maota, auā e leai se su’esu’ega fa’a’apea o fa’a i Niu Sila. O lenei su’esu’ega e avea ma se vaega ole fa’ailoga ole PhD lea oute faia i lalo ole ulutala “Fa’atāuaina ole Fa’amalōlōga ile Si’osi’omaga o Aiga”.

O lo’u auai ilenei su’esu’ega i lo’u loto faitaialia ma ‘e mafai ona fa’amuta lo’u auai i so’o se taimi. Oni fa’amatalaga ma ni fa’amaumuga mai ile ta talatalanoaga ole’a fa’aleaogaina ile lima tausaga mai le taimi ua uma ai lenei su’esu’ega. Ete u’umia le pule i ata uma ma latou kopī. Ole e ona lenei su’esu’ega, ole’a leai sona aiā i ata vagana ua iai seisi fa’atagaga mai le e ona ata. E mana’omia fo’i lou natia o se isī sa auai ilenei su’esu’ega. O talatalanoaga uma sa pu’ēina o lea ou tusia ise auala po’o se gagana e natia ai lē sa tufa mai. O nisi vaega ole’a latou va’ai ilenei su’esu’ega o a’u faufautuaga, ole Polofesa So’otaga o Philippa Howden-Chapman ma Foma’i Sarah Dean. O galuega uma sa aofia ilenei su’esu’ega ole’a fa’amaopo’opo ma tusia lea i se lipoti ona tu’u atu lea mo su’e’ega, ona teuina lea ile fale tusi olē univesite. O nisi fo’i vaega o nei su’esu’ega e mafai fo’i ona tu’u ina atu mo le fa’ailoa lautele i a’oa’oga maualuluga po’o le faia ai fo’i oni tufatufaga mo ni fonotaga.

O matāupu uma lava sa tatou fetuata’i ai e nanatia uma lava. Tasi lava le fa’atagaina ona ne’i iai se tulaga e lamatia ai lou tagata po’o seisi fo’i e afaina ai. Ole tiute lea olē sa faia le su’esu’ega e logo tagata e fetaui tonu ma le fa’afioa olea fa’afitauali.

Afa’i olo’o iai ni fesili po’o le fia malamalama atili e uiga i lenei saili’iliga, fa’amolemole vala’au mai po’o le fesili i lē sa tau a’aoina atu lenei tusi.

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**Po’o lou pule:**
Professor Philippa Howden Chapman 04 3855-999 extension 6047

“O lenei Su’esu’ega ua fa’aamaonia mai lea e le Univesite o Otago Komiti o le Human Ethics.

Fa’afetai lava mo lou fesoasoani. Manuia la’asaga ole aso.”
Appendix 7D.5 Information Sheet about Study for Home Detention for Detainee & Sponsor (English Language)

Information About The ‘Home Detention Study’

Project Title: Family-Centred Healing At Home.
Detainee & Sponsor Information Sheet [1.dt.ii]

Talofa Lava,

I am a Samoan student at the University of Otago. In 1995 I undertook a study with Samoan traditional healers to find out their views about Samoan people’s health experiences in the Wellington region. As a continuation of that study, I am seeking to explore key issues related to the Samoan peoples’ experiences of ‘healing at home’ particularly in relation to justice services (home detention) in the home and family environment, because there is very little information of this kind in New Zealand.

I would like to meet with you over a period of three months. During this time, you will be given disposable cameras to document your daily life. Specifically, participation in this project will involve:

a. Three to four meetings lasting no longer than three hours in total. The first meeting will be to introduce myself as the researcher and describe the study. A questionnaire about the study will be provided.

b. The second meeting, which will be at your home of residence, will be to offer you and your support person a camera each to document daily activities over a period of one month.

c. The third meeting is to talk about the photos and some of the areas of the study, which I would like to discuss in depth. The discussion at this session will be recorded on tape.

d. Reviewing transcripts of the interview as a means of checking that the information is accurate.

e. At the completion of the study, a gift and Summary Report of the Research Findings will be provided to you in acknowledgment of your time and participation. The gift is not a ‘reward or payment’, but a customary gesture of a mea alofa.

In the study, I would like to discuss with you a range of topics, such as, the health care you receive at home, what helps you the most in terms of dialysis, supports, aspects of fa’a Samoa (Samoan culture) and traditional healing (fofo Samoa) and the justice system in Aotearoa, New Zealand.

The benefits of participating in this research are to hopefully give you an opportunity to discuss some interesting issues about being a Samoan woman within the prison and community home detention environment. Wherever possible, relevant information that might improve the situation of Samoan prisoners in New Zealand will be forwarded to the Corrections Department, and that the information passed on will be described in a way so that it does not identify the people I have interviewed. Secondly, the project will contribute to professional and public knowledge and understanding of the experience of healing at home for Samoan families, about which currently no New Zealand research has been undertaken.
This study will be carried out as part of a PhD degree I am undertaking for a project called, “Family-Centred Healing At Home”.

The University requires that ethics approval be obtained for research involving people. Participation is voluntary and people who participate are free to withdraw at any stage from the study. The information and any data obtained from the participants will be destroyed five years after the study is completed. Participants will retain ownership and copyright of all their photographs and negatives. The researcher will have no access to photographs and/or negatives without the additional written permission of participants. Participants will be required to maintain the confidentiality of the others in the study. Tape-recorded data will be transcribed by myself and written up in such a way that participants will not be able to be identified. The only people aside from myself who will have access to the data will be my supervisors, Associate Professor Philippa Howden-Chapman and Dr. Sarah Dean. The material collected will be written up for a thesis to be submitted for examination and deposited in the University Library. Material may also be used in articles submitted for publication in academic or professional journals and for conference presentations.

While all the information that you as a participant might share with the Ramona Tiatia (researcher) is confidential, there will be only one situation where this may be not maintained. This would be a situation if the participant were in immanent or immediate potential danger to herself or to another person. In which case, the researcher would need to notify the necessary emergency services or relevant professional agencies.

If you have any other questions or would like to receive further information about the project, please contact me or ask the Corrections Officer who gave you this letter, to contact me at:

Ramona Tiatia  
PhD Research Fellow  
He Kainga Oranga/Housing and Health  
Wellington School of Medicine & Health Sciences  
PO Box 7343  
Wellington South  
Telephone: 04 3855-999 extension 4897  
Email: ramona.tiatia@stonebow.otago.ac.nz

Or my supervisor:  
Ass. Professor Philippa Howden Chapman 04 3855-999 extension 6047

“This project has been reviewed and approved by the University of Otago Human Ethics Committee”.

Fa’afetai lava mo lou fesoasoani. Manuia la’asaga ole aso.
Fa’afetai lava mo lou fesoasoani. Manuia la’asaga ole aso.

Summary Information Sheet
Form 3 Detainee Information Sheet [1.dt.ii]

HOME DETENTION STUDY
I am a PhD research student at the University of Otago, and I would like to talk to you about your experience of being a Samoan on home detention. I would like to come and meet with you at home. There is very little information about home detention. Hopefully the results of the study will help promote better understanding about Samoan people's experiences of home detention and prison life.

For the study I would like to:
- Meet with you and your sponsor and tell you about the study, and answer any questions you might have
- Collect your story by giving you disposable cameras to take photos (you can take up to 2 – 4 weeks to take your photos)
- Ask you to take photos on topics about what its like to be at home, things you do during the day, your views about Samoa and other topics you might be interested in
- Make a time to collect the cameras to be developed into photos, then drop these back to you (you can keep all the photos you shoot and I will provide a photo album for you to keep your photos in)
- Come back to talk to you and your sponsor about your photos, and to record our talk
- If you would like, I can give you a recorded copy of our talk and when the study is finished, return the film negatives of your photos
- Take the information from our talk and use it in ways you think might help others on home detention. I also want your permission to write it up in my thesis which will be put in book form in the University library, and to write papers to inform professional organisations about home detention

The information that you share with me will be treated confidentially. This means that your name will not be used. No information that might give away your identity or your family's identity will be used. If you want to pull out of the study at any time, you can. Taking part in this study will not affect you, good or bad, on any aspect of your involvement with the Department of Corrections.

If you have any other questions or would like to receive further information about the project, please contact me or ask the person who gave you this letter, to contact me at:
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PhD Research Fellow
He Kainga Oranga/Housing and Health
Wellington School of Medicine & Health Sciences
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Email: ramona.tiatia@stonebow.otago.ac.nz

“This project has been reviewed and approved by the University of Otago Human Ethics Committee”.

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Appendix 7D.7 Information Sheet about Study for Home Detention for Detainee (Samoan Language)

Fa’amatalaga mo le Fa’aauauina ole Fa’asalaga ile Aiga

Information Sheet – Detainee [1.dt.ii.s(1)]
Fomu 2: Fa’amatalaga mo le Soli Tulafono

O a’u ole Samoa oute a’oga ile Univesite o Otago. I le tausaga 1995, sa ou faia ai se su’esu’e ga i e ini o latou manatu po’o latou iloa e tau ile soifua maloloina o tagata Samoa i Uelinite. Ole fa’aauauina o le ne i su’esu’e ga, oute fia saili atili ni so’otaga o tagata Samoa ma lo latou malamalama ile fa’amalōlōga i aiga aemaise so’otaga auau naga ole tulafono ile si’osi’omaga ole aiga, auā, e le tele se fa’amatalaga e uiga i le nei latou matāupu i tonoto i Niusila.

Oute fia talosaga atu ete fa’aaoagaina le mea pu’e ata e fa’amatala ai ou manatu. Oute fiafia e pu’e ina au manatu i ata auā ‘e matagofie fo’i le taga’i i ata ilo’o le tau saili oni upu e fa’amatala ai ou manatu. Afai ete taliaina le nei su’esu’e ga oute avatu ina se mea pu’e ata (fa’aaga ma t’i’ai) ete pu’eina ai ni au galuuga fesoasoani mo oe ile tolu po’o fa vaiaso.

O mea olo’o ta’ua i lalo ole’a fesilidigia ai oe ile nei su’esu’ega:

a. O le’a e auai ini fonotaga se tolu po’o le fa ae le sili atu ile tolu itula le umi. O le nei fonotaga ole’a ou fa’ailoa atu lo’u nei tagata ma fa’amatala le uiga ole su’esu’ega mo oe ma lou fesoasoani. Olo’o iai se lisi o le nei polokalame ma ni fesilo mo le su’esu’ega e mafai ona avatu mo lou silafia. Afai ete finagalo malie ete auai ilenei su’esu’ega, ona ou mana’omia lea o lau saini mo le fa’atagaina fa’atatasi ai ma le faia ose isi taimoe fono ai ta’ua.

b. Ole fonotaga lua ole ofoina atu lea ose mea pu’eata (fa’aaga ma tia’i) mo oe ma e fa’amaumau ai mea olo’o tutupu mo ia’i oe ma se masina. Oute tu’uina atu fo’i ni matāupu e ta’i a lau pu’e ga ata. O mea e a’afia ai, olou si’osi’omaga ma lou lagofia mafutaga ma le aiga. E fa’alaba lava oe po’o a ata ete pu’eina ae oute fa’asino atu le fomu e tatau ona saini ‘e se tagata olo’o i tonoto ose ata tatou te fa’aogainai le nei su’esu’ega.

c. Ole fono lona tolu, ole talanoaga lea e uiga i ata ma ni matāupu tāua olenei su’esu’ega po’o ni matāupu fo’i ete fia talanoa atili ai e uiga ilenei su’esu’ega. Ole’a pu’eina fo’i lenei fonotaga ise lipine. Oute talatalanoa fo’i ia oe ma lau fesoasoani ta’i to’atasi. E mafai ona tatou talanoa fa’atasi pe’a uma ona pu’eina le lipine.

d. O le’a maua fo’i se avanoa e tu’uina atu pe ete fia faitau ina tusitusiga olole fa’atalanoaga, e avea fo’i ma se auala e fa’amaonia ai tusitusiuga ua fa’amaunia.

Ole tāua olou auai ilenei su’esu’ega ole tu’uina atu lea ose avanoa e fa’atalatalanoa ina ai ni matāupu matagofie e uiga i soli tulafono iē i tonoto ile falepui, ma le fa’aauauina mo le latou fa’asalaga ile si’osi’omaga ile latou nofoaga. Po’o le’a lava ni fa’amatalaga ma ni illi’liga e fa’aleleina atili ai tulaga o tagata falepui ma latou aiga i tonoto o Niu Sila olea tu’uina atu lea ile matāgaluega ole Tulafono. Ole’a tusia fo’i ise auala e natia ai lea sa ou fa’atalanoaina.

Olonu lua, o le nei saili’ilia ole’a lagolago tele mo tagata faigaluega ma lautele ina ia malamalama ma silafia le fa’amalōlōga mo aiga Samoa iō latou lava maota, auā e leai se su’esu’ega fa’apea o faia i Niu Sila. O le nei su’esu’ega e avea ma se vaega ole fa’ailopedia ole PhD lea oute faia i lalo ole ulu tala “Fa’atāuaina ole Fa’amalōlōga ile Sil’osi’omaga o Aiga”.

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O lo’u auai ilenei su’esu’ega i lo’u loto faiitalia ma ‘e mafai ona fa’amuta lo’u auai i so’o se taimi. Oni fa’amaatalaga ma ni fa’amaumau ga mai ile ta talatalanoaga ole’a fa’aleaogaina ile lima tausaga mai le taimi ua uma ai le le lenei su’esu’ega. Ete u’umia le pule i ata uma ma latou kopì. Ole è ona lenei su’esu’ega, ole’a leai sona aìa i ata vagana ua iai seisi fa’atagaga mai le èona ata. E mana’omia fo’i lou natia o se isi sa auai ilenei su’esu’ega. O talatalanoaga uma sa pu’eina o lea ou tusia ise auala po’o se gagana e natia ai lè sa tufa mai. O nisi vaega ole’a latou va’ai ilenei su’esu’ega o a’u faufautuaga, ole Polofesa So’otaga o Philippa Howden-Chapman ma Foma’i Sarah Dean. O galuega uma sa aofia ilenei su’esu’ega ole’a fa’amâopoopo ma tusia lea i se lipoti ona tu’u atu lea mo su’e, ona teuina lea ile fale tusi ole univesite. O nisi fo’i vaega o nei su’esu’ega e mafai fo’i ona tu’u ina atu mo le fai’alioa lautele i a’oa’oga maualuluga po’o le faia ai fo’i oni tufatufaga mo ni fonotaga.

O matāupu uma lava sa tatou fetufa’ai ai e nanatia uma lava. Tasi lava le fa’atagaina ona ne’i iai se tulaga e lamatia ai lou tagata po’o seisi fo’i e afaina ai. Ole tiute lea olē sa faia le su’esu’ega è logo tagata e fetau tonu ma le fa’afoia olea fa’aftauli.

Afai olo’o iai ni fesili po’o le fia malamalama atili e uiga i lenei sail’iliga, fa’amole mole vala’au mai po’o le fesili i lē sa tau a’aoina atu lenei tusi.

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“O lenei Su’esu’ega ua fa’aamaonia mai lea e le Univesite o Otago Komiti o le Human Ethics.

Fa’afetai lava mo lou fesoasoani. Manuia la’asaga ole aso.
Appendix 7D.8 Information Sheet about Study for Home Detention for Sponsor (Samoan Language)

Fa’amatalaga mo le Fa’aauauina ole Fa’asalaga ile Aiga

Information Sheet – Sponsor [1.s.ii.s(i)]

Fomu 5: Fa’amatalaga mo le Va’aia le Soli Tulafono

O a’u ole Samoa oute aoga ile Univesite o Otago. I le tausaga 1995, sa ou faia ai se su’esu’ega i e uiga i fofo Samoa (taulasea), ini o latou manatu po’o latou iloa e tau ile sofua malōlōina o tagata Samoa i Uelinitone. Ole fa’aaauuina o lenei su’esu’ega, oute fia saili atili ni so’otaga o tagata Samoa ma lo latou malamalama ile fa’amalōlōga i aiga ae aemaise le so’otaga auauuaga ole tulafono ile si’osi’omaga ole aiga, auā, e le tele se fa’amatalaga e uiga i lenei matāupu i tonu‘o i Niusila.

Ote fia feiloa’i mo oe, ole o lo’o va’aia le soli tulafono. Olē ua soli tulafono ua auai lenei su’esu’ega ma olo’a a latou fesiligia lou fa’atagaina o lou talanoa mai ia te a’u. Oute fia malamalama i lou iloa ma ni ou manatu e uiga ile matāupu ole fa’aaauuina ole fa’asalaga ile aiga. O nisi nei matāupu ou te fesili atu ai ia te oe, fa’aopea le ua soli tulafono, olea le ituaga auauuaga o lo’o lua mauaina ile aiga. Olea se auauuaga e mafai ona fa’afio’ai ai ni fa’aftauali oia oe.

Oute fia talosaga atu fa’aaoaonaia le ma pe’u’u ata e fa’amatala ai ou manatu. Oute fiafia e pu’u’i ina au manatu i ata auā ‘e matagofie fo’i le taga’i i ata ilo’o le tau saili oni upu e fa’amatala ai ou manatu. Afai ete talaiaina lenei su’esu’ega ote avatu ina se mea pu’e ata (fa’aaoa ma ti’ai) ete pu’eina ai ni ou galuega fesoasoani mo oe ile tulou po’o fa vaiaso.

O mea olo’o taua i lalo olea fesiligia ai oe ilenei su’esu’ega:

i. O le’a e auai ini fonotaga se tulou po’o le fa ae le sili atu ile tulou itula le umi. O lenei fonotaga ole’a ou fa’aioa atu lo’u nei tagata ma fa’amatala le uiga ole su’esu’ega mo oe na’o oe. Olo’o iaia se lisi o lenei polokalame ma ni fesili mo le su’esu’ega e mafai ona avatu mo lou silafia. Afai ete finagalo malie ete auai ilenei su’esu’ega, ona ou mana’omia lea o lou saini mo le fa’tagainia fa’atasi ai ma le faia ose isi taimi toe fono ai ta’ua.

ii. Ole fonotaga lua ole ofoina atu lea ose mea pu’eata mo oe ma le soli tulafono e fa’amaumau ai mea olo’o tutupu ile lua mafutaga mo se masina. Ote tu’uina atu foi ni matāupu e ta’ala ile lua pu’e’ega ata. O mea e a’afia ai olou maota po’o lea se auala e fesoasoani ai e fa’alelei ai lou sofua malōlōina ma nisi lava mea e a’afia ai lou sofua malōlōina, o oe oe tagatanu’u Samoa. E faitalia lava oe po’o a ata ete pu’eina ae oute fa’asino atu le fomu e tatau ona sainia ese tagata olo’o i tonu‘o ote ata tatau te fa’aogaina ilenei su’esu’ega.

iii. Ole fono lona tulou, ole talanoaga lea e uiga e atu ma ni matāupu tāua olenei su’esu’ega po’o ni matāupu fo’i ete fia talanoa atili ai e uiga ilenei su’esu’ega. Ole’a pu’eina fo’i lenei fonotaga ise lipine. Ote talatalanoa fo’i ia oe ma tai to’atasi. E mafai ona tatu tulanoa fa’atasi ma le tama’ita’ai tausipe’a uma ona pu’eina le lipine.

iv. O le’a maua fo’i se avanoa e tu’uina atu pe ete fia faitau ina tusitusiga olenei fa’atalanoaaga, e avea fo’i ma se auala e fa’amaonia ai tusitusiga ua ou fa’amauina.
Ole tāua olou auai ilenei su’esu’ega ole tu’uina atu lea ose avanoa e fa’atalatalanoa ina ai ni matāupu matagofie e uiga i soli tulafono iē i totonu i le latou ile falepuipui, ma le fa’aauauina mo le latou fā’asalaga ile s’ōsi’omaga ile latou nofoaga. Po’o le’a lava ni fa’amatalaga ma ni ili’ila’iga fa’aleleina ati lea tulaga o tagata falepuipui ma latou aiga i totonu o Niu Sila o lea tinuina atu lea ile matāgaluega ole Tulafono. Ole’a tusia fo’i ise auala e natia ati lea ili sa ou fa’atalanoaina.

Olona lua, o leinei saili’iliga ole’a lagolago tele mo tagata faigaluega ma le lautele ina ia malamalama ma silafia le fa’amalolōga mo aiga Samoa iō latou lava maota, auā e leai se su’esu’ega fa’apea o faia i Niu Sila. O lenei su’esu’ega e avea ma se vaega ole fa’ailoga ole PhD lea ou faita auai ile auai ile sa so se taimi. Oni fa’amatalaga ma ni fa’amaumauga mai ile ta talatalanoaga ole’a fa’alaeagoaina ile lima tausaga mai le taimi ua ai ailei su’esu’ega. Ete u’umia le pule ile atu ile ma latou kopi. Ole ē ona leinei su’esu’ega, ole’a leai sono aiā i ata vagana ua iai seisi fa’atagaga mai le ēona ati. E mana’omia fo’i lou natia o se isi sa auai ilenei su’esu’ega. O talatalanoaga uma sa pu’eina o lea ou tusia ise auala po’o se gagana e natia ai lē sa tufa mai. O nisi vaega ole’a latou va’ai ilenei su’esu’ega o au’u faufautuaga, ole Po’o leilūa So’otaga o Philippa Howden-Chapman ma Foma’i Sarah Dean. O galuega uma sa aofia ilenei su’esu’ega ole’a fa’amāopopo ma tusia lea i se lipoti ona tu’u atu lea mo su’e’ega, ona teuina lea ile fa’alogai fa’ama’ao ma tusia lea i se lipoti ona tu’u atu lea mo su’e’ega ole’a fa’amalolōga ile S’ōsi’omaga ile Aiga”.

O lo’u auai ilenei su’esu’ega i lo’u loto fa’aitalia ma ‘e mafai ona fa’ama’utu lo’u auai i so se taimi. Oni fa’amatalaga ma ni fa’amaumauga mai ile ta talatalanoaga ole’a fa’alaeagoaina ile lima tausaga mai le taimi ua ai ailei su’esu’ega. Ete u’umia le pule ile atu ma latou kopi. Ole ē ona leinei su’esu’ega, ole’a leai sono aiā i ata vagana ua iai seisi fa’atagaga mai le ēona ati. E mana’omia fo’i lou natia o se isi sa auai ilenei su’esu’ega. O talatalanoaga uma sa pu’eina o lea ou tusia ise auala po’o se gagana e natia ai lē sa tufa mai. O nisi vaega ole’a latou va’ai ilenei su’esu’ega o au’u faufautuaga, ole Po’o leilūa So’otaga o Philippa Howden-Chapman ma Foma’i Sarah Dean. O galuega uma sa aofia ilenei su’esu’ega ole’a fa’amāopopo ma tusia lea i se lipoti ona tu’u atu lea mo su’e’ega, ona teuina lea ile fa’alogai fa’ama’ao ma tusia lea i se lipoti ona tu’u atu lea mo su’e’ega ole’a fa’amalolōga ile S’ōsi’omaga ile Aiga”.

O lenei su’esu’ega u’a fa’ama’utu mai lea e le Univesite o Otago Komiti o le Human Ethics.

Ramona Tiati
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Po’o lou pule:
Professor Philippa Howden Chapman 04 3855-999 extension 6047

“O lenei Su’esu’ega ua fa’amaonia mai lea e le Univesite o Otago Komiti o le Human Ethics.

Fa’afetai lava mo lou fesoasoani. Manuia la’asaga ole aso
Title of Project: Family-Centred Healing At Home  (Home Dialysis Study)

- I have read the Information Sheet. I have been given an explanation of this research project and have understood this explanation.
- I have had an opportunity to ask questions and have had them answered to my satisfaction.
- I understand that my participation will involve being interviewed and filling in a questionnaire.
- I understand that I may withdraw from the project any time.
- I understand that any information I provide will be kept confidential to the researcher and her supervisors.
- I undertake to keep confidential any information that any other participants in the study provide.
- I understand that my participation in this study is confidential and that no material, which could identify my household or me, will be used in any reports on this study.
- I understand that no photographs taken by me for the purpose of this research project can be published without my written permission.
- I understand that the tape recording of the interview will be electronically wiped at the end of the project and that all transcripts will be destroyed within five years of the thesis being completed.
- I understand that the data I provide will not be used for any other purpose other than those stated in the information sheet, nor will it be released to others, without my written consent.
- I have had time to consider whether to take part.
- I know whom to contact if I have any questions about the study.

I consent to take part in this study.

<table>
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<tr>
<th>Participant’s Signature</th>
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<tr>
<td>Name (Print)</td>
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<td>Date</td>
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I would like to receive a Summary Report of this Study:  (Tick one)  Yes ☐ No ☐

“This project has been reviewed and approved by the University of Otago Human Ethics Committee”

Fa’afetai lava mo lo’u fesoasoani. Manuia la’asaga ole aso.”
Appendix 7E.1 Consent Form for Dialysis Study (Samoan Language)

Ulutala O Su’esu’ega: Fa’atāuaina ole Fa’amalolōga ile Si’osi’omaga ole Aiga (Fa’amāmāina ole Toto)
Dialysis Carer Consent to Participate [2.c.iii.s(1)]

Form 13: Fa’atagaina ole Auai mo Tamaitai Tausi Ma’i mo Lē e Fa’aaogaina le Fa’amāmā Toto [2.c.iii.s(i)]

- Ua ou faitauina le Laupepa ole Fa’amatalaga. Sa fa’amalamalama ina mai le uiga olenei su’esu’ega ma ua ou malamalama i le fa’amalamalaga.
- Ua tu’uina mai le avanoa oute tu’uina atu ai ni fesili ma ua ou malie i tali.
- Oute malalalama i lo’u auai, ole’a fesiligia a’u ini matāupu ese’ese ma ole’a tu’uina mai ise auala fa’anatia, ma e mafai ona ou le talia se fesili oute le mana’o ai.
- Oute malalalama fo’i e mafai ona ou tu’umulii mai lenei su’esu’ega i so’o se taimi.
- Oute malalalama so’o se talanoaga oute auai ma lē fia le su’esu’ega, e natia lea na’o i ia ma lana pule.
- Oute natia fo’i so’o se fa’amatalaga a nisi olo’o auai ilenei su’esu’ega.
- Oute malalalama olo’u auai ilenei su’esu’ega e natia fa’apea ma ni fa’amatalaga e fa’aaoga mo lipoti e fesili ao i lana pule.
- Oute malalalama fo’i e leai se ata oute pu’eina mo lenei su’esu’ega e fa’aaogaina mo nisi tusitusiga e aunoa ma la’u fa’atagaina.
- Oute malalalama olelipine sa pu’eina ole’a fa’aleaga ina ile fa’ai’uga ole su’esu’ega. O tusitusiga uma olenei su’esu’ega ole’a fa’alēaogaina ile 5 tausaga talu ona uma lenei su’esu’ega.
- Oute malalalama oni fa’amatalaga sa ou ofoina atu e le mafai ona fa’aaogaina mo seisi lava auala vagana ai lenei su’esu’ega po’o le avatu fo’i ise’isi e aunoa ma la’u fa’atagaina.
- Ua tu’u mai le taimi oute iloilo ai pe oute auai ilenei su’esu’ega.
- Oute iloa ina fa’afeso’otai lē o faia le su’esu’ega po’o ana pule fo’i i iau na ma tuatasi ua tusia mai, pe’a fai e iai ni a’u fesili.

Ua ou malie oute auai ilenei su’esu’ega.

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<th>Saini</th>
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<td>Igoa (lolomi)</td>
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<td>Aso</td>
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Oute fia maua ina le Lipoti olenei su’esu’ega: (Fa’ailoga le Tasi) loe a Leai a

Afa’i e iai nisi fesili po’o mana’omia nisi fa’amatalaga e uiga ilenei su’esu’ega, Telefoni mai le olo’o faia le su’esu’ega ma lana pule:

Ramona Tiatia  
PhD Student  
He Kaiinga Oranga/Housing & Health Wellington School of Medicine & Health Sciences  
PO Box 7343  
Wellington South

Telephone: 04 3855-999  
Extension 4897  
Cell: 021-266-1553  
Email: ramona.tiatia@stonebow.otago.ac.nz

Researcher Supervisors:
Professor Philippa Howden-Chapman  
04 3855-999 Extn 6047  
Dr. Sarah Dean 04 3855-999 Extn 6124

"O lenei Su’esu’ega ua fa’amaonia mai lea e le Univesite o Otago Komiti o le Human Ethics." Fa’afetai lava mo lo’u fesoasoani. Manuia la’asaga ole aso.
Appendix 7E.2 Consent to Contact Participant – Home Detention Study Form (English Language)

HOME DETENTION STUDY Consent To Contact Form

I am a PhD research student at the University of Otago, and I would like to talk to you about your experience of being a Samoan woman in a prison environment, and your experience of home detention. I would like to come and meet with you in prison, and then later when you are at home continuing your sentence on home detention. The results of the study will help promote better understanding about Samoan women prisoner’s experiences of home detention and prison life.

The information that you share with me will be treated confidentially and you will be able to pull out of the study at any time. Taking part in this interview will have no effect, good or bad, on any aspect of your interactions with the Department of Corrections.

This form gives permission for Ramona Tiatia from the University of Otago, Housing and Health, Wellington Medical School, to contact you in the near future to carry out an interview to talk to you about prison and home detention in your home. If you agree to be contacted, you will be asked for a meeting with Ramona Tiatia, so that she can come and talk with you to explain what the study is about. Ramona Tiatia may be given my first name only and that no other information will be sought or given by the Department of Corrections unless Ramona Tiatia has my written permission to do so.

I_________________________________ have read (or have had read to me) and understand the above and give my permission to be contacted by Ramona Tiatia (researcher).

Participant’s Signature

Date

Referring Officer (Name) ________________ Signature ______________

Date: __________

Corrections personnel please return in self-addressed envelopes provided and send to:

Ramona Tiatia
PhD Research Fellow
He Kainga Oranga/Housing and Health
Wellington School of Medicine & Health Sciences
PO Box 7343
Wellington South

Telephone: 04 3855-999 extension 4897
Email: ramona.tiatia@stonebow.otago.ac.nz

“This project has been reviewed and approved by the University of Otago Human Ethics Committee”.

Fa’afetai lava mo lou fesoasoani. Manuia la’asaga ole aso.
Appendix 7E.3 Consent to Contact Participant – Home Detention Study Form (Samoan Language)

HOME DETENTION STUDY
Fa’atagaina ole Fa’afeso’ota’iga mo le Tagata Soli Tulafono Detainee Consent Form Form 1[1.dt.i.s(i)]

O lo’o faia sa’u su’esu’ega ile Universite o Otago. Oute fia talanoa ma oe ‘e uiga i lou lagona ma lou silafia fa’atama’ita’i Samoa i totonu ole fale puipui fa’aapea fo’i ma lou silafia ole fa’asalaga fa’aauau ile aiga. Oute fia alu atu’e fa’afeilao’i ma oe ile fale puipui fa’aapea fo’i pe’a fa’aauau atu lau fa’asalaga ile aiga. Ole taunu’uga olenei saili’iliga ‘e fesoasoani lea mo le fa’amalamalama ina atili o Tamaitai Samoa i totonu o falepuipui.

O fa’amatalaga ete ‘e tufa mai ia te a’u ole’a fa’ananaina. E mafai ona ‘e tu’umuli mai lenei su’esu’ega i so’o se taimi. E leal sou afaina ile ‘auai ilenei fa’atalanoaaga, po’o le lelei po’o le leaga, i totonu ole Matagaluega o Tulafono.

Olenei pepa e fa’atagaina ai Ramona Tiatia mai le Univesite o Otago, Housing and Health, Wellington Medical School, ‘e fa’afeso’ota’i atu ai oe ise taimi lata mai, e talatalanoa ai le mataupu e pei ona ta’ua i luga, olou silafia ile ologa totonu ole falepuipui mai le fa’aauauina ole fa’asalaga ile aiga.

Afaite finagalo malie ‘e fa’afeso’ota’i oe, ole’a faia se taimi mo se lua feiloa‘iga ma Ramona Tiatia olea fa’amatala atu ai ‘e ia le autu olenei saili’iliga.

E mafia ona ave atu ‘e Ramona na’o lo’u igoa muamua. Oute le fa’atagaina ona ave atu nisi fa’amatalaga ‘e aunoa ma lo’u saini pepa.

O a’u……………………………………..ua ou faitau (pe sa faitauina mai ia te a’u) ma malamalama i tusitusi oigai luga ua avatu la’u fa’atagaga ‘e fa’afeso’ota’i mai a’u e Ramona Tiatia. (Saili’iliga/Researcher). Date_____________

Referring Officer (Name) _____________________ Signature _______

Date_______

Corrections personnel please return in self-addressed envelopes provided and send to:

Ramona Tiatia
PhD Research Fellow
He Kainga Oranga/Housing and Health
Wellington School of Medicine & Health Sciences
PO Box 7343
Wellington South

Telephone: 04 3855-999 extension 4897
Email: Ramona.tiatia@stonebow.otago.ac.nz

“O lenei Su’esu’ega ua fa’amaonia mai lea e le Univesite o Otago Komiti o le Human Ethics.

Fa’afetai lava mo lou fesoasoani. la manuia la’asaga ole aso.
Appendix 7E.4 Consent Form – Home Detention Study (English Language)

Consent to Participate Form

**Title of Project:** Family-Centred Healing At Home (Home Detention Study)

- I have read the Information Sheet. I have been given an explanation of this research project and have understood this explanation.
- I have had an opportunity to ask questions and have had them answered to my satisfaction.
- I understand that my participation will involve being interviewed and filling in a questionnaire.
- I understand that I may withdraw from the project any time.
- I understand that any information I provide will be kept confidential to the researcher and her supervisors.
- I undertake to keep confidential any information that any other participants in the study provide.
- I understand that my participation in this study is confidential and that no material, which could identify my household or me, will be used in any reports on this study.
- I understand that no photographs taken by me for the purpose of this research project can be published without my written permission.
- I understand that the tape recording of the interview will be electronically wiped at the end of the project and that all transcripts will be destroyed within five years of the thesis being completed.
- I understand that the data I provide will not be used for any other purpose other than those stated in the information sheet, nor will it be released to others, without my written consent.
- I have had time to consider whether to take part.
- I know whom to contact if I have any questions about the study.

**I consent to take part in this study.**

<table>
<thead>
<tr>
<th>Participant’s Signature</th>
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<tbody>
<tr>
<td>Name (Print)</td>
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<td>Date</td>
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</table>

I consent to allow Ramona Tiatia for the purpose of this study to view a copy of:

I would like to receive a Summary Report of this Study: (Tick one)  
1. Yes  2. No

*This project has been reviewed and approved by the University of Otago Human Ethics Committee*. 
Appendix 7E.5 Consent Form – Home Detention Study (Samoan Language)

Ulutala O Su’esu’ega: Fa’atāuaina mo le Fa’aauauina ole Fa’asalaga ile Aiga

- ua ou faitauina le Laupepa ole Fa’amatalaga. Sa fa’amalamalama ina mai le uiga olenei su’esu’ega ma ua ou malamalama i le fa’amalamalaga.
- ua tu’uina mai le avanoa oule tu’uina ata ai ni fesili ma ua ou malie i tali.
- oule malamalama i lo’u auai, ole’a fesiliga a’u ini matāupu ese’esu mai ise auala fa’anatia, ma e mafai ona ou le talia se fesili oule ou mana’o ai.
- oule malamalama fo’i e mafai ona ou tu’umuli mai le nei su’esu’ega i soo se taimi.
- oule malamalama so’o se talanoaga oule auai ma lē faia le su’esu’ega, e natia lea na’o ia ma lana pule.
- oule natia fo’i so’o se fa’amatalaga a nisi olo’a auai ilenei su’esu’ega.
- oule malamalama olo’u auai ilenei su’esu’ega e natia fa’aapea ma ni fa’amatalaga e fa’aaga mo lipoti e iloa ai lo’u aiga po’o a’u.
- oule malamalama fo’i e leai se ata oule pu’eina mo le nei su’esu’ega e fa’aogaina mo nisi tusitusiga e aunoa ma la’u fa’atagaina.
- oule malamalama ole lipine sa pu’eina ole’a fa’aleaga ina ile fa’ai’uga ole su’esu’ega. O tusitusiga uma olenei su’esu’ega ole’a fa’alēaogaina ile 5 tausaga talu ona uma leinei su’esu’ega.
- oule malamalama oni fa’amatalaga sa ou ofoina atu e le mafai ona fa’aogaina mo seisi lava auala vagana ai lenei su’esu’ega po’o le avatu fo’i iseisi e aunoa ma la’u fa’atagaina.
- ua tu’u mai le taimi oule iloilo ai pe oule ouai ilenei su’esu’ega.
- oule iloa ina fa’afeso’ota’i lē o faia le su’esu’ega po’o ana pule fo’i i numera ma tuatusi ua tusia mai, pe’a faia e iai ni a’u fesili.

Ua ou malie oule auai ilenei su’esu’ega.

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<thead>
<tr>
<th>Saini</th>
<th>Igoa (lolomi)</th>
<th>Aso</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Oute fia maua ina le Lipoti olenei su’esu’ega: (Fa’ailoga le Tasi ) loe a Leai a</td>
</tr>
</tbody>
</table>

Afa i iai nisi fesili po’o mana’omia nisi fa’amatalaga e uiga ilenei su’esu’ega, Telefono mai le olo’a faia le su’esu’ega ma lana pule:

Ramona Tiatia
PhD Student
He Kainga Oranga/Housing & Health
Wellington School of Medicine & Health Sciences
PO Box 7343
Wellington South
Phone: 04 3855-999
Extension 4897
Cell: 021-266-1553
Email: ramona.tiatia@otago.ac.nz

Researcher Supervisors:
Professor Philippa Howden-Chapman
04 3855-999 Extn 6047
Dr. Sarah Dean 04 3855-999 Extn 6124

“O leini Su’esu’ega ua fa’amaonia mai lea e le Univesite o Otago Komiti o le Human Ethics.”
Fa’afetai lava mo lo’u fesoasoani. Manuia la’asaga ole aso
Appendix 7E.6 Participant Consent to Photograph Form

Consent to Photograph [1.dt.iv] Film ….., Shot …..

I acknowledge that my picture is being taken by [ ] as part of her involvement in Ramona Tiatia’s Thesis research project “Family Centred Healing At Home”.

I consent to the resulting photograph, if selected by [ ], to be used for discussion purposes in a confidential interview with Ramona Tiatia (researcher), as well as it being published and displayed in conjunction with the research findings.

Name ___________________    Signature ___________________

Fa’aloaina ma Fa’atagina Fomu [1.dt.iv.s(i)]    Film …..  Shot……

Ua ou iloaina lenei ata ua pu’eina e [igoa ] ona oloana auai fa’atasi ile mataupu olo’o su’esu’eina e Ramona Tiatia. Ole mataupu (Fa’atauaina ole Fa’amalologa I le Siosi’omaga ole Aiga) atonu fo’i’e fa’aaoagina ‘e Ramona i lana sailiiliga.

Oute fa’atagaina le taunu’uga onei ata, pea fa’ai ‘e filifilia e [igoa ] ia fa’aaoagina ini fa’atalanoaga ma ni tusitusiga fa’atasi ma ni mataupu ole taunu’uga lenei su’esu’eega. E fa’anatia uma suafa onei gaoioiga uma.

Igoa_(name)_____________    Saini_(signature)_______________________
Guide To Taking Your Photos for the Study

Taking Care of Your Camera

- The Disposable Camera you have will need to be kept dry at all times, so please keep it in the plastic bag when you are not using it.
- Make sure you turn the flash on, if you’re taking photos inside or if light in the room is not very bright and always at night time.
- If something happens to your camera and it gets damaged or lost, please ring me and I will come back with another camera for you. Don’t get worried about it, because it is a disposable camera and it can be replaced very easily.

What Kind of Photos Should I Take?

Could you please take photos that we can talk about them when I come back in a few weeks. As you know the study is about how you and your family live with dialysis. Please feel free to take pictures about whatever you like. You can take pictures inside your home or outside your home. If you want to take pictures of people, then please check that they are happy for you to take the photo. We may have to get written permission from them if we decide later to use the photo.

Here are some ideas to help you:

- What in your home helps you to be well?
- Are there any special places, objects, or rooms that are important to you?
- Do you go out of your house for appointments, to do shopping, church or to visit other people? Are there any interesting places or things that you see when you’re out travelling?
- Is there anything that reminds you in your home or outside of your home, about what life was like for you, before you started on dialysis treatment?
- Is there anything that you miss doing or people you miss?
- What does it mean to be a Samoan person living with dialysis?

The 5 Steps We Will Take?

Step 1: Ramona drops the camera off to you:

I will leave the camera with you today on: __________________
Step 2: You take your photos over 2 weeks
There are 25 shots in your camera. You have up to two weeks to take your photos, and I will ring you to ask when I can come and pick your camera up, so that I can take it to develop. If you need more time, then please let me know when I ring you.

Step 3: Ramona comes back & picks up the camera to take to develop the film
Ramona will ring you for a good time to come and pick up the camera on ____________________.

Step 4: Ramona brings the photos back & talk about photos
When I’ve developed the camera film, I will come back and show you the photos, and ask if we can talk about it. I will ask if it’s all right to record our talk.
During our talk, I will ask you about using the photos that you agree can be used in the study, and which ones cannot be used. Remember, the photos are really there to help talk. After our talk if you would not like the photos to be used, then, that is okay. I will leave all the photos with you and make a note of the ones that we have talked about.

Step 5: Ramona will contact you again to send you the information from your interview & the study
If you want a copy of our talk I can send it to you when I’ve written it up.
If at anytime you want to change your mind about being part of the study, then, please feel free to let me know, and I will understand.

Ia Soifuaina,

Ramona Tiatia

Fa’afetai lava mo lou fesoasoani. Manuia la’asaga ole aso.

Please feel free to ring me if you need to:
Telephone: 04 3855-999 extension 4897 or
Cell: 021-266-1553

Email: ramona.tiatia@stonebow.otago.ac.nz

Or my Supervisor:
Professor Philippa Howden Chapman 04 3855-999 extension 6047

“This project has been reviewed and approved by the University of Otago Human Ethics Committee.”
19th September 2006

[Sponsor Name]
[Address]

Talofa Lava,

Re: Home Detention Study

Thank you very much for agreeing today to talk to me about this study on Home Detention and for considering being part of it.

I have enclosed an Information Sheet (green in Samoa) that tells you everything about the study. I hope that it is easy to follow and please feel free to contact me if you have any questions.

As I explained on the telefoni, I will courier your camera to you and [detainee’s name]. There is a paper (yellow colour) to explain how to use the camera and the photos that you might want to take. I will give you a telephone call in about one and a half weeks (around the 29th September 06) to see how you’re going and if you need more time to take your photos, or if you want to ask me any questions at all about the study.

In the courier bag, there is another spare Courier Bag to mail back your cameras to me. When you and [detainee’s name] are ready to send back your cameras, please put them into the Courier Bag.

Then, please just ring 0800 800 841 and the NZ Couriers Company will come to your house to pick up the bag to bring back to my Wellington address. You do not have to pay anything for it, as it is already being paid for by my organisation.
When I receive the Cameras, I will take them to develop and I will phone you about a good time when I can come to your home to talk about the photos. In our talk today, you said that there might be a chance that [detainee’s name] will be called back to Wellington or sent to Auckland to serve out her sentence. If that happens, then, I am happy to meet with you in Wellington or Auckland if this would be easier for you and [detainee’s name].

I have also enclosed a Consent Form (white Samoa) for you to read and if you agree, can you please sign and send back with the cameras.

If there is any reason that you might change your mind and decide not to do the study then I will understand, and ask if you can please just let me know.

I hope that all is well with your family and look forward to talking with you in a few weeks.

*Ia Soifuaina*

Ramona Tiatia  
PhD Student  
He Kainga Oranga/Housing and Health  
Wellington School of Medicine & Health Sciences  
PO Box 7343  
Wellington South  
Telephone: 04 3855-999 extension 4897  
Cell: 021-266-1553

Email: ramona.tiatia@stonebow.otago.ac.nz
Appendix 7G In-Depth and Open-Ended Questions

Home Dialysis Open-ended Questions

Specific Questions - Home Dialysis Families

- How would you describe your quality of life living with dialysis?
- Are there any things you used to do before you started treatment that you miss doing?
- What helps you keep well?
- Have you ever considered kidney transplant? Has this been something your family has discussed?
- Have you and your family discussed your last days and where you might be buried?
- Is there an alagaupu (proverbial sayings) or bible verse or saying that describe your experience of living with dialysis?
- What was your experience of home dialysis? What type of dialysis treatment did you use?
- What is dialysing at home like compared to the hospital renal unit?

Home Detention Open-ended Questions

Specific Questions for Home Detention Families

- What is your experience of prison
- What is your prison cell like
- What do you miss most while you're in prison
- Tell me about your family
- What do you expect to do when you get released on home detention
- What are your views about Samoan prisoner offending – causes, interventions, attitudes
- Are there differences and similarities between Samoan born and New Zealand offenders within prison environment
- What are your views about Samoan culture discipline, identity, protocols?
- Ifoga (Samoan protocol related to apology and forgiveness between an offending party towards the victim), it’s perceived effectiveness and ineffectiveness, practice in New Zealand and Samoa?
- What kind of home is suitable for home detention?
July 20, 2005

Ms Ramona Tiatia
PhD Fellow
169 Mitchell Street
Brooklyn
WELLINGTON

Dear Ramona,

I have received your proposal to carry out as part of your PhD study, a case study on home detention as part of justice services in the home.

I support this proposal in principle and can see at this stage, no impediment to your proposal to conduct in-depth interviews with Samoan female prisoners.

Yours sincerely,

[Signature]

J L Castell
Prison Manager
Arohata Women’s Prison
Appendix 7I Research Agreement with Department of Corrections

Department of Corrections

Research Agreement

The Department of Corrections supports research of issues pertinent to its area of responsibility. The Department allows researchers access to its institutions and to offenders to facilitate such research. Because of the Department’s custodial responsibilities, and its duty to provide safe and humane containment of inmates, such research can only be carried out within the agreed guidelines, as outlined in this document.

This document sets out an agreement between Ramona Tiatia of He Kainga Oranga Housing and Health and the Department of Corrections to allow Ramona Tiatia (“the researcher”), to conduct research within the Department of Corrections facilities and with Departmental clients and/or staff.

This research is called: Family Centred Healing at Home.

Permission to undertake this research is granted on the following conditions:

1. The research has been endorsed by a University Head of Department or researcher supervisor, or manager of a reputable research-related organisation.

2. The researcher has approval from an accredited institutional ethics committee, or the proposal has been reviewed by a recognised human ethics body.

3. The researcher will obtain informed consent from all research participants or respondents, keep a record of that consent, and provide the Department of Corrections with evidence of that consent. Informed consent means an agreement to participate in the research and includes:
   a) the participants being informed of the purpose, nature and procedures of the research;
   b) the participants being informed of any research procedures that might have harmful effects on them;
   c) the participants being informed of their right to withdraw from the research at any stage, and that exercising the choice to withdraw would not disadvantage them in any way; and
   d) the participants being informed they have the right to know how the data may be used, and of the outcome of the study.

4. During the course of the research, the researcher will at all times respect the working environment in which the research is undertaken. The researcher will meet the Department’s requirements relating to access to any institution and to clients of the Department.

5. The researcher will take all possible steps to protect the participants from discomfort, distress or embarrassment. Participants’ welfare and dignity will take precedence over the requirements of the research at all times.
6 Any information which could lead to participants’ identification will not appear in any form (verbal or written information) in the thesis document, any publication, teaching or presentations.

7 The researcher knows and understands that permission to undertake the research is conditional upon compliance with the requirements of the Privacy Act 1993. In particular the researcher understands that he/she is obliged, under the provisions of that statute, to ensure that:

- the information gained will be used solely for purposes directly linked to the research project, and will not be published in a form that could reasonably be expected to identify any individual [Principles 10(f)(i), 10(f)(ii), 11(h)(i), and 11(h)(ii)]; and

- no other person, other than a person assisting the researcher with the analysis or research, will have access to participants’ personal information. In particular, the researcher will ensure that the information is protected by such security safeguards as is reasonable under the circumstances to take, against loss [Principle 5(a)(i)]; access, modification or disclosure [Principle 5(a)(ii)].

8 The researcher will not photocopy or remove any Departmental records consulted in the course of the research.

9 Where information is disclosed to the researcher that signals risks to the safety and welfare of participants or other persons, these concerns shall be brought to the attention of the relevant Unit or Service Manager in the first instance, as well as the Senior Strategic Adviser responsible for research approvals.

10 Other than information being gathered for the research and other than information disclosed as per paragraph 8 above, the researcher agrees to keep confidential all information about the Department of Corrections and its operations to which the researcher becomes privy.

11 Information obtained for the research will only be disclosed in the manner agreed with the Department of Corrections, as outlined in paragraphs 12 to 15 below.

12 The researcher understands and agrees that:

- the Department may wish to make alterations to the content of a report to correct factual inaccuracies;

- any content changes would be fully discussed with the researcher beforehand;

- the Department may ask for the document to carry a disclaimer stating that the thesis does not represent the views of the Department of Corrections.

13 The researcher agrees that, after the completion of the process outlined in paragraph 12, the researcher will provide three copies of the research report or thesis. One will be for the use of the Service that has provided the context for the research, one for the Policy Development Group that manages the Department’s research programme, and one to be lodged
Department of Corrections Research Agreement

with the Department’s Information Centre. The researcher will keep the Department fully informed of any publication of the research findings. (Publication includes lodging of research report(s) in any library, or any other dissemination of the completed research).

14 Neither party shall make any public comment or presentation about the completed thesis or research report without the agreement of the other party.

15 Should there be media interest arising from the publication of the completed research, the Department will manage that media activity, on either a reactive or proactive basis, in consultation with the researcher. The Department may wish to provide additional material to the media or the public to give context to the research report or thesis.

16 The researcher will at all times abide by the code of ethics of the profession to which the researcher belongs through the course of the research project.

Signed

For the researcher

P. L. Howden-Chapman
Prof P. L. Howden-Chapman
Supervisor

Name: Ramona Tiatia
Designation: Researcher
Date: 14/6/07

For the Department of Corrections

Name: Jane von Dadelszen
Designation: General Manager
Policy Development
Date: 4/5/07
Dear Ms Castell

Re: Progress Report – Home Detention Study

I would like to take this opportunity to thank you for your support in allowing me to carry out my study. I am pleased to provide you with this brief progress report of the work to date.

Interviews

To date I have completed eight interviews since the period of June to October 2006. Written consent was sought from each participant and they were informed of the right to withdraw from the study at any time.

All participants are of Samoan ethnicity, had been referred from Arohata Prison and interviewed face-to-face by the researcher (Ramona Tiatia) using digital audio recording format. The participants comprised of:

- prison officers (4);
- prisoners (3) serving or intending to serve out home detention;
- detainee’s validated sponsor (1)

The average length of the recorded interviews range from 1 to 1.30 hours. Participants were offered the option of receiving transcripts or recordings of their interviews.

At the completion of each interview three prisoners were given cameras to take photos of their cell whilst in the presence of a duty prison officer. These photos have been developed and distributed when the prisoner is released to serve home detention. This has been the case for only one prisoner who, with their validated sponsor were given cameras to take photos of their day-to-day lives on home detention. The researcher interviewed this couple in early October.
Participant Withdrawal

To date, only one participant has withdrawn (female prisoner while serving home detention) citing the reason for leaving the study was to ‘start a new life and to put everything behind her’. The information provided by this participant will be excluded from the study. Hence, only seven of the eight interviews and the data collected from these interviews (and any other subsequent interviews from new participants) will be used and discussed for the purposes of the study.

Questions

All participants were asked a range of questions relating to their views on the following topics:

- Samoan prisoner offending – causes, interventions, attitudes
- Differences and similarities between Samoan born and New Zealand offenders within prison environment
- Samoan culture and views related to family, discipline, identity, protocols
- Ifoga (Samoan protocol related to apology and forgiveness between an offending party towards the victim), it’s perceived effectiveness and ineffectiveness, practice in New Zealand and Samoa
- Home detention as an option for community sentencing (advantages, disadvantages, perspectives of sponsors versus detainees)
- Life in prison, current programmes and perspectives on reintegrating to community and family life

Emergent Themes from Interview Transcripts

Prison Officers

- Echoed similar perceptions about the differences between prisoners born in Samoa with those born in New Zealand. The later often displaying characteristics such as: being younger, lacking remorse about their offending, showing less interest in their Samoan identity, showing less observances of religious rituals and beliefs
- Most believed that home detention was useful for first offenders particularly if there was adequate family support for the detainee, and responsibilities to child care
- Family values about respect towards elders, financial responsibility towards life events such as funerals, marriages and the like viewed as providing positive reinforcement for Samoan culture
- Peer pressure identified as a contributing factor for increasing number of youth offenders; whilst, serious assault crimes amongst older Samoan women were often related to spousal infidelities; whilst in the case of Samoan woman fraudsters it was commonly propagated myth “that they did it because of too many fa’alavelave (financial family debts)” despite, according to prisoner officers view that the reality is the fraudsters families often saw very little of the money that was stolen
- That Ifoga is an important protocol still viewed highly effective amongst offending and victimised families when carried out in its proper context
- That home detention would have increased effectiveness if the detainee is matched correctly with relevant community based programme interventions such as educational activities, counselling, vocational training
Were happy to contribute to the study as a means of supporting the work of Pacific prison officers working with Pacific prisoners in New Zealand prisons

Prisoners

- First offences and prison sentences
- Reflections about their time in prison as ‘time to think’, ‘time out’
- Identified potential fears about not being able complete home detention
- Values related to respecting ones elders and supporting the family are considered important, despite the conflicting disagreements with certain authority figures within their family
- Had previous knowledge about Ifoga and viewed it as significant for the families they knew of; understood the purpose of Ifoga and relevance as Samoan protocol for justice and making amends for wrong doing and effecting peaceful relations
- Hopes of taking advantage of home detention to betterment of life choices towards one’s family and future goals
- Since imprisonment admitted to having regrets of making wasteful choices and often recounted the moment when they could have reversed the events that led to their offending, stating that they would not repeat it in the future
- Were happy to participate in the study as a means of contributing to assisting other Samoan prisoners and their families

Validated Sponsor

- Has a positive appreciation of home detention upon the detainee as it increases the time the detainee is forced to spend at home with the family
- Sees the advantages of home detention as a deterrent on the detainee’s behaviour particularly in relation to restricting access to criminal associates and getting into trouble outside
- Having detainee at home is a better preference than prison because of the financial difficulties related to travelling to prison for visitations
- Home detention allows the sponsor the opportunity of being able to receive practical support from family and friends that would have otherwise been denied if the detainee were in prison
- Was happy to participate in the study as a means of contributing information to assist Samoan youth prisoners and their families

So far this work has proven to be of great interest to both participants and researcher (and supporting Supervisors). Whilst, the information provided here is really a brief summary it is envisioned that the recommendations offered by the participants at this stage of the study, would be of value in relation to understanding some current issues of the prison environment from the perspectives Samoan prison officers and offenders.

I hope that this progress report is adequate and provides some helpful description of what the study has aimed to achieve in relation to its philosophical and practical objectives. Please feel free to contact me if you require any further information. I would also appreciate your comments about the information provided here and your consent to present this information to the PhD Advisory group meeting next week on the 24th October. I have received your apologies and also Jacky Jones for not being
able to attend and wonder if you will be sending another representative. Again I'd like to thank you Janet for the support that you and your staff have provided for my study.

Yours sincerely,

Ramona Tiatia  
PhD Researcher Student  
He Kainga Oranga/Housing and Health  
Wellington School of Medicine & Health Sciences  
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Wellington South  
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c.c Prof. Philippa Howden-Chapman; Dr. Sarah Dean
Appendix 7K Dissemination of Findings

Seminar and Conference Presentations

February 2012
University of Otago, Wellington. Summer School, Pacific Health.

September 2011
University of Otago, Wellington. PUBH702 Post-Graduate Lecture Course.

April 13 2010 Auckland University Post-Graduate Seminar, Tribute to Epeli Hauofa, Department of Pacific Studies.

August 31st, 2010

August 2007
Building Research Capacity in the Social Sciences, PhD national teleconference circuit Victoria University.

Meetings

Summary of findings

30th August 2012
Presentation and gifting of home dialysis photographs to the Hon. Minister of Health, Samoa, Tuitama Dr. Talalelei Tuitama and the Dir. General of Health, Samoa, Palanitina Toelupe, Dean of Oceania University, Dr. Lemalu Limbo Fiu, General Manager of the Samoa Kidney Foundation, Mulipola Roger Hazelman, Assistant Manager of Corporate Services, Sose Taulelei. Meeting was hosted by the Pacific Directorate, Capital Coast and District Health Board (Taima Fagaloa and Bella Bartley) with the Pacific Advisory Group.

14th December 2011
Dr. Murray Leikis, Clinical Leader, Dr. Grant Pidgeon, Wellington Renal Unit, Regional Hospital, Capital Coast and Health District Health Board.
Team Leader, Ms. Mary Mallon. Wellington Renal Unit, Regional Hospital, Capital Coast and Health District Health Board.

Outcome: A funding proposal in association with the Capital District Health Board, Pacific Directorate and supported by the Wellington Regional Hospital, Renal Unit to the Ministry of Health, via Pacific Perspectives Ltd, Dr. Debbie Ryan to work collaboratively with relevant agencies to support ‘integrated services’ for Pacific renal patients. After nearly 6 months of negotiating and up to 8 months of waiting for the final outcome, the project unfortunately was not approved.
6th October 2010
- Clinical Director, Long-Term Conditions Unit, Dr. Grant Pidgeon, Wellington Renal Unit, Regional Hospital, Capital Coast and Health District Health Board.
- Taima Fagaloa, Director, Pacific Unit, Regional Hospital, Capital Coast and Health District Health Board.
- Astuti Balram, Long-term Conditions Unit, Regional Hospital, Capital Coast and Health District Health Board.

Outcome: A funding proposal was submitted to Funding and Planning Unit, CCDHB to support a photographic exhibition and community education programme to Pacific communities was submitted (project ongoing).

8th July 2010
Clinical Leader, Dr. Grant Pidgeon, Wellington Renal Unit, Regional Hospital, Capital Coast and Health District Health Board.

6th October 2009
Project Manager, Renal Services, RCSP Dawn Kelly. Central Region’s Technical Advisory Services Ltd.

Outcome: TAS ran two focus groups with Pacific dialysis patients at the Porirua Satellite Clinic about ways to improve services.

31st October 2007
Manager of Arohata Women’s Prison, Ms. Jacky Jones

27th October 2007

27th November 2007
Team Leader, Ms. Mary Mallon. Wellington Renal Unit, Regional Hospital, Capital Coast and Health District Health Board.

7th November 2007
Senior Pacific Advisor, Crime Prevention Unit, Ministry of Justice, Mr. Norman Tuiasau

August 2005
National Pacific Advisor Viko Aufaga, Department of Corrections.
Appendix 8.1 Photo Set (Ata)

Participant Photo Set 1 Ata (Home Dialysis Study)
Appendix 8.2 Photo Set (Efu)

Participant Photo Set 1  Efu at dialysis satellite unit (Home Dialysis Study)
Appendix 8.3 Photo Set (Emo)

Participant Photo Set 1 Emo (Home Dialysis Study)
Appendix 8.4 Photo Set (le)

Participant Photo Set 1 IE (Home Dialysis Study)
Appendix 8.5 Photo Set (IVI)
Appendix 8.6 Photo Set (Ofe)

Participant Photo Set 1 OFE (Home Dialysis Study)
Appendix 8.7 Photo Set (Osi)

Participant Photo Set  OSI (Home dialysis study)
Appendix 8.8 Photo Set (Ufi)

Participant Photo Set 2 UFI (Home dialysis study)
Appendix 8.9 Photo Set (Uga)

Participant Photo Set 3 UGA (Home dialysis study)
Appendix 8.10 Photo Set (Uso)

Participant Photo Set 4  USO (Home dialysis study)
Appendix 8.11 Photo Set (Usu)

Participant Photo Set 1 USU (Home dialysis study)
Appendix 8.12 Photo Set (Foe)

Home Detention Study

Participant Photo Set 5 FOE (Home detention study) Inside prison.
Participant Photo Set 2 FOE (Home detention)  Outside electronic perimeter’s and Foe’s tattoo (photo altered to disguise tattoo)
Participant Photo Set 3  FOE (home detention study). Life on home detention
Appendix 8.13 Photo Set (Galuā)

Participant Photo Set 6 GALUĀ (Home detention study) Inside prison
Participant Photo Set 7 GALUĀ (Home detention study). Surveillance equipment and perimeter fences
Participant Photo Set 8 GALUĀ (Home detention study). At home
Appendix 8.14 Photo Set (Tulutulu)

Participant Photo Set 9 TULUTULU (Home detention study)
RESULTS

- Home Dialysis Photographs and Themes
- Three participants produced photographs within the hospital built environment setting (i.e., Ivi, Efu). Efu asked me to take a photograph of him at a satellite unit when I visited him. Most participants made photos of some aspect of the dialysis treatment routine and included pictures of dialysis disposables and equipment.

Family 1 Ata

- Total Photographs n=26
- Photo themes
- Photographs of photographs mostly of family and friends of the church (n=11)
- Early Samoan settlers
- Landscape and streetscape views of surrounding neighbourhood areas (n=10)
- Renovation of kitchen (n=3)
- Kitchen appliances (n=1)
- Coping with the cold and changes in wellbeing (n=3)
**Interview Transcript themes**

- Early Pacific settlers to the Wellington area during the 1950s and 1960s
- Establishing the foundation Pacific church and “styles of leadership and service”
- Experiences of the Wellington Children’s Hospital and the authority of the doctors within the public health system
- Life as a patient inside of the Wellington Dialysis Unit between patients who are “able” and “unable” to dialyse with assistance from staff
- The impact of the ‘patient empowerment policy’ and opposition to the new schedule.
- Issues related to travelling to the Porirua Satellite Unit
- Increased physical and emotional deterioration on dialysis
- The differences between staff, those who “work with love” and those who “don’t care and work for money”.
- Two matching donors and refusal to kidney transplantation
- Concerns about home dialysis and fear of electrical appliances on heart-pace-maker

**Family 2 Efu and Emo**

Total Photographs: Efu n=30, Emo n=27

**Photo themes**

- Photograph of self actively engaged in household duties (Ef u n=25, Emo n=24)
- Gardening (Ef u n=9, Emo n=4); indoor cleaning (Emo n=4); hanging washing (Ef u n=2, Emo n=1);
- Favourite outdoor places (Ef u n= 2, Emo n=1)
- Workspaces for earning income at home (Ef u n=3, Emo n=3)
- Pictures of grandchildren (Ef u n=2, Emo n=1)
- State housing accommodation & issues of storage (Ef u n=1, Emo n=1)
- Complained about the high transport costs and the problems of understanding the National Travel Assistance Fund that subsidised patients living km from renal clinic
- Patient undergoing haemodialysis at satellite in-unit clinic (Efū n=2)
- Medical storage at home (Efū n=1, Emo n=1)
- Dialysis consumables (Efū n=1)

**Interview Transcript themes**
- Family move from Samoa to Aotearoa/NZ for improved medical care for renal condition (housing, renal specialist)
• ‘E le fa’atu’u ile ma’i’ (To never give in to the disease) underpins Efu’s approach to coping and responding to long-term illness with specific meanings that are embedded in cultural concepts and Samoan geomentality

• Tatau (pe’a, male tattoo) forms an identification of Samoan masculinity and a framework for understanding the physiology of pain, emotional distress and Samoan spiritual values related to endurance, suffering, humility and respect. The symbolism of the tatau is steeped in architectural (Samoan building), landscape (trees, branches, plants), oceanic (sea, fish, netting) and animistic (bird, bat) motifs.

• Samoan notions of hospitality, healing and death are provided in Samoan culture (Aganu’u). From his insider experience as a Samoan orator Efu describes Samoan ocean tides (Tai Samasama, Vai Sā) and genealogical-politico arrangements (Tuimanu’a, Malietoa & Tuitoga) to contextualise these notions in relation to living with CKD.

• Transport costs of travelling from home to in-unit satellite clinic in another city

• Efu’s switch from home-CAPD to haemodialysis-in-unit

• Emo’s refusal for the uptake of home haemodialysis because of the issues around compliance

• Perceived risks of assisted home-dialysis for carers and the formal implications of medical harm to the patient

• Housing New Zealand tenancy and provision of a modified three bedroom house suitable for tenants with disability and mobility requirements

• Surrendering employment and desire to earn income as a dialysing family

• Responsibilities as child-carers (grandchildren), leaders (church), matai (chiefly obligations to extended family and village)

• Decision not to transplant and plans for future burial

Family 3 Ie and Ivi

• Total Photographs: Ie set 1 n=36, set 2 n=2, Ivi n=26
Photo themes
- At the dialysis Unit (le n=2, lvi n=1)
- Photos of the hospital shuttle and family vehicle
- Margaret Stewart House (le n=3, lvi n=1)
- Bedroom (n=1)
- Storage area at home for dialysis supplies (n=2)
- Photos of siblings (le n=3)
- Streetscape scenes of local playgrounds, train depot, streets and city buildings (le n=1, lvi n=10) and open landscape scene (n=1).
- Church (le n=1, lvi n=2)
- Family outings (le n=6; lvi n=11)
- Photographs of grandparent (le n=5).
- Inside of a vehicle (le n=1, lvi n=3)
- At work (le n=2; lvi n=5)
- Medical spaces at home (le n=3, lvi n=1), hospital (le n=4, n=1) and satellite unit (le n=5).
- Photographs of children (le n= 6, lvi n=8) and extended family (le n=5, lvi n=2).

Interview Transcript themes
- The family’s history of living in private and state rental residential properties
- lvi (mother/carer) struggled for years trying to understand clinicians’ ‘medical speak’. She recounted the hardship of having little income, borrowing family vehicles, not affording public train fares and spending long hours at the hospital with her daughter without meals.
- Dampness and lack of storage was a consistent issue in all the homes the lived in
- Renovation of the HCNZ family house increased the living spaces for the family. However, as a consequence the properties were difficult to warm and this led to increased electricity bills through running heaters in the house.
- Financial hardship associated with high transport costs to the Wellington Dialysis Unit
Disappointment and anger of not being told for three years that ‘hospital free shuttle’ service operated between Wellington and Porirua

Ivi was constantly borrowing vehicles whenever she could from extended family members to get to Ie’s hospital appointments/treatments

Margaret Stewart House and the gruelling dialysis schedule

The convenience of switching from in-hospital to home dialysis and the increased demands and expectations that was placed on the children to assist Ie with home dialysis

Ie’s desire as a young adult for ‘independence’ and “space” at home forced her to spend more time at her grandfather’s house. There she could get reprieve from her parents and her younger siblings.

Not long after making the decision to abandon home haemodialysis Ie moved out from her parent’s house to live with her grandfather on a permanent basis.

The ongoing issues about storage and the costs of electricity and disconnection problems contributed to having the machine returned

Ivi’s financial burden of fuel debt and the switch to ‘pre-pay metering’ and consequences of disconnection on the family, particularly on Ie’s haemodialysis treatment

The religious and cultural aetiology of chronic kidney disease and associated meaning of ‘family curse’, promulgated by Ivi’s father

The importance of family support, youth church group, music and singing in the church band

Ivi’s grandmother who had also been a dialysis patient, made Ivi swear not to let Ie pass away in the hospital and to never show her anger while she cared for her.

Issues for younger dialysis patients are unique and different from older patients

Ie disliked the protocols related to the way that staff on Ward 40 handled the notification of patients’ deaths and informing other patients’

As Ie reflects on the option of kidney transplantation and awaited the results of the matchup tests for her and her mother, she talked about the ongoing chronic complications with her fistula.

Dialysis treatment and episodic infections had disrupted Ie’s study commitments and her prospects of continued employment. She desired to
travel overseas, especially to Samoa and had already investigated the possibility of going there where there to the new renal clinic in Apia.

**Family 4 Olo, Osi and Ofe**

Total Photographs Ofe n = 89; Osi n=28

Photo themes
- Household appliances used as in CAPD medical routine: microwave (Osi n=1, Ofe set 2 n=3); washing machine (Osi n=2; Ofe set1 n=1, set2 n=2); television (Osi n=1, Ofe set2=1)
- Medical appliances used in medical routine: adjustable bed (Ofe set3 n=4); intravenous drip pole (Ofe set3 n=3)
- Medical furniture used in medical routine: serving table (Ofe set3 n=1), wheelchair (Ofe set3 n=2), commode (Ofe set3 n=1)
- Household appliances used for medical storage: refrigerator (Osi=1, Ofe set2 n=3)
- Household rooms used for medical storage: bedroom (Ofe set1 n=1, set2 n=1, set3 n=5; Osi n=1); dining room/kitchen (Ofe set2 n=3, set3 n=5; Ose n=1)
- Dialysis disposables: sanitary napkins (Osi n=1; Ose set1 n=1, set3 n=1)
- Access barriers to daily care routine: shower over bath (Ofi n=2, Ose set2 n=5)
- Access in relation to emergency alternatives: through front door (Ose ; backdoor
- Medical waste: disposal of outside (Osi n=2, Ofe set3 n=2)
- Disrupted sleep (Osi n=1; Ofe set1 n=2, set2 n=3, set3 n=3)
- Indoor quiet/passive activities (Ofe set1 n=1, set2 n=1, set3 n=2; Ofi n=1)
- Spiritually associated objects: mirror (Ofe set2 n=4, set3 n=1); bible (Osi n=1),

**Interview Transcript themes**

- Olo viewed home dialysis in a positive way, encouraged Samoan families to take it up because of the convenience and continuation of ordinary activities.
- Gendered arrangements about areas of responsibilities and duties of care which were the feminine domain in Samoan families was carried out by Olo (father) and Ofe (brother); it was acknowledged this was discontinuity of traditional roles
• Formalised use of Samoan metaphorical speech associated to the long-term illness of a family member are important to acknowledge in Samoan families
• “UfifuiUfifui o manu gase” (The protective covering or the concealment of an afflicted bird).
• Efu matua’i apulu lava tofaga, aulia le fala, taulia le fale efu’, (Ashes, dust, rubbings, chaffing is endured, complete, deposited, covers, reaches the mat and sleeping place, hence the arrival and entry into the house of ashes).260
• Inadequacy of the NASC (Needs Assessment of Services & Co-ordination) carried out with the family resulted in failed follow-up
• The family were not provided with adequate explanation or information about how to access/hire/purchase suitable medical equipment, medical furniture for palliative renal care of their family member
• On-going difficulty about the patient’s mobility to hospital appointments
• The Patient (Oli) had been offered a donated cadaver but refused it, the decision was supported by her husband (Olo); both parents decided to exclude their children (Ofe and Osi) from the decision by not telling them about the donated kidney; children respected the decision without question at the time; being involved in the study helped them to think about why their parents had refused transplantation
• Deferred employment for carers during most difficult time of caring for the patient
• Issues emerged in relation to disposal of medical waste and family members felt stigmatised whenever putting out their rubbish for weekly council street collection
• The taken-for-granted storage of medical supplies in several interior rooms particularly the kitchen/dining rooms, bedrooms, laundry; medication in household refrigerator
• Importance of creating an aesthetic space for Mum’s palliative care and the increased appreciation of the surrounding walls, ceilings and furnishings which serve as spaces for passive activities such as prayer, reading, lying in bed, listening to choir music, listening to Samoan language radio, watching outside the window.

260 The descriptions were offered by Lavea Tupuola Malifa (assisting the researcher as co-interviewer), as a reflection of the story that Olo provided about the care that he, his immediate and extended family collectively provided. This was an appropriate and respectful response from Lavea as an acknowledgement of Olo’s leadership status as a Chief, and the honouring of Olo’s deceased wife, and the long-term unwellness she endured and the family’s collective response to the provision of care for her.
The various spaces in the house that indicated both symbolic and spiritual phenomena associated to wellbeing, the presence of deceased family members and the preparatory journey to death.

- The importance of the co-existence between Christianity and Samoan cultural values.

**Family 5 Uso, Uga, Usu and Ufiufi**

**Total Photographs: Uso n=10, Uga n=11, Usu n=5, Ufiufi n=17**

**Photo themes**
- Photographs of places of employment photographs (Uga n=1, Ufiufi n=1)
- Patient dialysing at home (Uga n=1, Usu n=1, Ufiufi n=1)
- Family celebrations: holiday in Samoa (Uso n=2)
- Religious and spiritual community (Uso n=1, Uga n=2, Ufiufi n=2)
- Photographs of photographs: wall (Uga n=1, Ufiufi n=1); shelf (Ufiufi n=1)
- Household appliance used during medical routine: television (Uso n=1, Uga n=1, Ufiufi n=1, Usu n=1); clock (Ufiufi)
- Inactive time at home: relaxing (Uso n=1, Uga n=2, Ufiufi n=2, Usu n=2)
- Special Object: shoes (Uga n=1), first car (Uga n=1), card (Uga n=1), fishing catch (Usu n=1)
- Photo of family dog (Uso n=1, Uga n=2)
- Usu total photos n=5 he took, includes a photo that Uga provided of Usu’s fish.

**Interview Transcript themes**
- Issues of maintaining “normality” and integrating dialysis into the every day routine of family life. This also included the shared hope amongst all the family members that kidney transplantation would give Uso the opportunities of life such as world travel, long life, career, marriage and children.
- Continuance and flexibility of Uso’s paid employment within the family business
- Reduction of paid hours for Uga (carer, mother) to assist with Uso’s dialysis schedule
- Maintaining a sterile and adequate treatment space at the family home for Uso while he continued to living at his flat in town; and renovation of an existing room (family office)
Impact of kidney failure on the youngest family member and catalyst to leaving school.

The reality for Usu (father) as he struggled to accept his son’s condition and the adjustment for the family members.

Hospital car parking and travelling more than 120km return from home to Wellington.

It was 3 months of travelling to dialysis treatment 3 times a week before Uga said she found out, by accident that patients/families were entitled to $5 subsidised car parking fees. Disappointed that there was no information.

Usu’s travelling expenses from home to hospital, National Travel Assistance delayed payments Uso, he was awaiting a $600 reimbursement, and had already submitted a previous amount of $1,200 for approximately four months worth of travel.

Haemodialysis training for patients was a new experience that Usu thoroughly enjoyed; however, he could empathise with non-English speaking patients who would find the training difficult to comprehend.

Uso suggested ideas of extending the level of follow-up that home haemodialysis patients get before they complete the 8 week training at Margaret Stewart, recommending that they try for at least 2 weeks on their own at the clinic before commencing on their own at home with greater confidence.

The one visit in the first week and one telephone in the first month was inadequate because home dialysis patients immediately lose the medical support and social interaction with others, an aspect that Uso said he had greatly underestimated when he started treatment at home.

Uso found it difficult to understand why so many older Pacific Samoan patients dialysed at the hospital instead of at home. He felt that if increased support could be provided by a paramedical-trained network such as St. John’s Ambulance, it would dramatically increase the uptake of home haemodialysis. Older patients required assistance with the insertion of needles because of frailty and lack of confidence.

Patients that dialysed at home should also expect prompter return of blood results and be able to have fuller nutritional consultations.

One of the obvious issues that Uifui noticed at the renal hospital was the age differentials between younger and older patients. She wished that the renal
clinic environment could be more conducive to the needs and experiences of young people.

- Transplantation was an obvious choice for all the family members. Uso could not understand why most of the Pacific patients, including the younger ones were not registered on the national donor cadaver registry. He felt there was a great need to improve Pacific people’s perceptions about transplantation through education in the wider community.

**Uso, Uga, Usu, Ufiufi – photos**

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<th>Dialysis</th>
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<th>Uga</th>
<th>Usu</th>
<th>Ufiufi</th>
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Appendix 10  Photo Themes Home Detention Study – Additional Notes

Analyses of the photographs and the textual descriptions have been carried out to examine data collected at the two different locations:
1) Detainees and Prison Officers at the State Prison Facility;
2) Detainees and Sponsors at the Home Detention Residence.

Introduction of Detainee Photographs

In this section, I summarise the participants’ photographs by key themes. An outline of the total number of photographs that each participant produced with a brief description of the range of images produced per collection of photographs.

Photographs of Prison Inside

Foe and Galuā talk about the first set of photographs that were taken of their former prison cells.261 As both Foe and Galuā talked in detail about their photographs, various themes emerged about aspects of imprisonment that differentiated the two separate environments of institution and home, formal and informal responsibilities, familial and official relationships.

Photographs of Home Imprisonment on the Outside

The women were asked to view the second set of photographs that they had taken of their life on home detention. A range of complex issues are depicted providing insight about the Samoan family domestic environment and what occurs when regulated home detention is enforced on Samoan prisoners and their families. The sets of photographs allowed the women to talk about how they adjusted to being electronically monitored 24 hours a day (at week 25 for Galuā and weeks 36 and 72 for Foe) 262; and how this compared to being locked in a state facility. One of the important aspects of home detention that emerges from the data is related to a detainee’s right to privacy, protection and wellbeing within the family domestic domain.

Foe (Detainee)
Total Photographs n= 29

Summary about Photograph Sets

Experiences of state prison (Aggregate themes from Interview Transcripts 1, 2 and 3)

- Life in the “Prison Wings” and four violent altercations with other prisoners;
- “having a job” within the prison facility and then becoming “unemployed” in the final month before being released;

261 Galuā did not have the opportunity to ask the sponsor (Tulutulu) about the photographs she took of her former prison cell. Foe on the other hand, was able to talk about her family’s response to her photographs and during the interview this was discussed.

262 Foe: Interview 1, June 2006 (prison) Interview 2, April 2007 (home detention); Interview 3 November, 2007 (probation). Galuā: Interview 1, June 2006 (prison); Interview 2, October 2006 (home detention).
• “family support” while she was inside and the anxiety of having to learn how to live with her birth mother and siblings for the first time; Foe’s expectations of home detention.

Experiences of Home detention (Key photographic themes discussed at Interviews 2 and 3)

• House as prison, PMU Box, wearing the electronic bracelet, electronic perimeters;
• Probation Officer/Chubbs Security surveillance checks and supervision;
• use of time to “paint the house”, “get rid of the stones” to dismantle the umu (earthen oven pit), “pulling out the weeds”, and beautifying the house and outdoor areas;
• sentencing plan, “going to counselling” to address the over-use of alcohol;
• Adjustment to family, siblings and extended aiga “getting on with the old lady”, family dynamics and the role of eldest daughter at home;
• “trying to get a job”, the stigma of being an offender, being known to the victim’s family;
• “dealing with the boredom”, restricted movement, adapting to surveillance equipment and Corrections monitoring;
• Dilemma of planned outings and authorised visits, “I could’ve done a computer course all this time”;
• Putting up with being sick, no health and doctor visits;
• Disappointment with CPS:
  • Stigmatisation, disapproval from victim’s networks, failure to secure employment and be accepted into a sports team;
• Future plans, employment and re-integration;
• Recommendations for the study.

Galuā (Detainee)
Total Photographs n= 41

Experiences of State Prison (Aggregate themes from Interviews Transcripts 1 and 2):

• “life on Segs (Segregated Status)” as a 16 year old in prison
• “wishing to be in the circle”, during religious services
• “the desk” as a place that she wrote letters and music lyrics for her co-offender/boyfriend
• “treat mum like a queen”, advice from older prisoners
• “want to travel the world”, desire to finish school and travel
• expectations of home detention

Experiences of Home detention (Key themes from photographs discussed at Interview 2):

• “missing the silences”, and time on her own at home;
• “who I used to be”, youth gang identity;
• “the people who surround me”, familial and social network of support;
• “the Mana wahine course I did”, the wall hanging and my identity;
• “the tree, the telephone”, restricted movement under surveillance;
• “I breached”, not complying to conditions of sentence and being locked in the cells when her sponsor goes away for a funeral;
• “under the mat”, Ifoga as restorative justice conducted by the family at a Family Group Conference (FGC), its impact and implications for moving forward;
• “Corrections dishonesty”, disappointment that home detention did not fulfil the expectations;
Experiences of wearing the electronic anklet, living with the home monitoring unit and electronic boundary, interactions with Correctional staff, probation officers and security guards.

Tulutulu (Sponsor)
Total Photographs n= 24

Summary of Home detention Photos
Most of Tulutulu’s photographs are of herself accompanied by other people. Other photographs are of her daughter Galuā (detainee), granddaughter and friends. All the photographs were taken in and outside of their family home.

1. Experiences of Home detention (Key themes from photographs discussed at Interview 1):
   • Her role as a Sponsor for Galuā (detainee/participant);
   • family life on home detention;
   • Close friends as support for day to day tasks such as shopping, supervision and encouragement;
   • Breach and events leading up to it;
   • The ‘tree’, restricted movements and responsibility of care for the detainee, the “good things” about home detention;
   • Ifoga as restorative justice, attempts to apologise to the victim, disappointment in the state’s facilitation role;
   • Religious and spiritual faith.
Appendix 11 Origins of Samoan Culture

11A Golden Ocean Tide – Tai Samasama

In summing up his perspectives about living with dialysis, Efu talked enthusiastically about the importance of Samoan language (gagana samoa) and land (agaifanua) by using two stories to reinforce the importance of Samoan cultural identity and Samoan geomentumality. The Tuimanu’a is considered as the progenitor from ancient times of the customs and traditions that spread through all the Samoa islands. He held political governance over all the Samoa islands including other Pacific groups of the time including Tonga. The two stories that Efu narrated comes from his knowledge as an orator and his use of the stories in lauga (speeches/salutations). There are cultural meanings which Efu connects intimately with because it gives purpose and significance to his contemporary private and public situations. What becomes highlighted are the deep symbolic and metaphorical concepts which Efu identified that are important to Samoan social identity.

The Samoan ocean tide called Tai Samasama (Tide Golden/Yellow) is a coastal area of the Ta’u (Manu’a-a-tele) Island in the Manu’a Group (eastern region of Samoa, American territory). Various geological reports give origin to the name is a coastal area of which outlines some of the socio-politico-historical origins of the highly ritualized Samoan ceremonial exchanges of feminine (toga) and masculine (oloa) gifts defined as Samoan cultural wealth (Appendix). It is an historical account between two ancient Samoan rulers, the Tuimanu’a 263 (from Samoa’s eastern region) and Malietoa (Samoa’s western region). The Tuimanu’a hosted the Malietoa and then gifted a range of cultural wealth (oloa) consisting of live stock (pigs, gaming birds and fowls), sacred fishes and harvested plants (like taro) for the journey home. More significantly however, the gifts also included a range of complex protocols related to the ceremonial division of cooked foods (poultry and pork) which is formally presented and distributed across the stratified Samoan levels of Chiefs and non-Chiefs within the Samoan hierarchical system. The same hospitality was reciprocated at a later period by the Malietoa to the Tuimanu’a; the Taisamasama commemorates this alliance and is recounted in Samoan oral history.

263 The Tripartite Convention of 1899 divided the unified Samoan chain of ten main islands in the Pacific Ocean. The western most islands went to Germany, the eastern to America. New Zealand occupied Western Samoa in 1920 until it became independent in 1962. Customs and traditions, genealogical and historical exchanges unified all the Samoan islands and districts despite the political partitioning.
Efū: Everything that Tuimanu’a offered when they had been hosted was returned: I’a sā (Sacred Fish) from your waters, which thrives here in the sea has been killed here for you; the Pig that roamed in your pigsty, has been brought to be divided; your Talo that was planted on your mountain, it has been harvested; your I’a Sā (Sacred bird), that roamed your land, they are here too. Everything that you provided for us that was slaughtered; we offer you our deepest spirit of thanks. And so we return to Samoa with a nourished and a canoe that has rested with the setting sun. These words are Malietoa’s, his thanks to the Tuimanu’a at the time he was being hosted by him and his people – this is the origins of the Tai Samasama.

11B The Tuimanu’a’s Spring Pool & The Healing Of The Tuitoga

The second story is another historical account involving the Tuimanu’a with the another ancient ruler of the Pacific Ocean, the Tuitonga. After being cautioned to avoid certain sacred land and water sites, an incident occurs where a member of the Tongan party is found dead at a bathing pool that was restricted for use only by the Tuimanu’a. The story emulates the compassion and healing authority of the Tuimanu’a who had the Tongan resuscitated back to life by sacred chant.

Efū: The Tuimanu’a had hosted the Tuitoga for at least a month and said, “No matter whatever happens, ensure that there is just one important thing that you must be careful of, and that is, not to bathe in the Tuimanu’a’s pool.” However, the Tuitoga disobeyed and he died immediately. To try to save him, the Tongans started to chant, “I Toga, e! I Toga, e!” The chief Warrior of the Tuimanu’a heard this and reported the incident to the Tuimanu’a. The Warrior instructed the Tongans to change the chant to: “Le Tuimanu’a e, le Tuimanu’a, e”. The Tongan was revived and began to breath.

Samoan Translation

Efū: O’o loa ina fia foi Malietoa i Samoa faia ia Tuimanu’a “Ilou agaalofa ma lou agalelei, o lau l’a sa ta’a ilou gatai a? Ole l’a foi le gale sa ta’a ile sami ‘ai ua fa’amate mai; lau pua’a sa ta’a ilona sai, ia lea ua fa’avai mai; lau talo sa toto I lou mauga, I lea ua fafai mai; lau moa sa ta’a ilou paepae, ia o moa foi
nae, a? Aua, o mea na sa tausi ai ia lea ua mate mai, momoli atu ai le agaga faafetai tele a lea matou foi Samoa ma le mama ua lomi ma le vaa ua goto a?
Upu ia a Malietoa, olana faafetai na ia Tuimanu’a ile taimi na tausi ai ia ao le mea lena na mafua mai le upu lena le Tai Samasama.

Ia e tele a tele a nisi fa’amaumauga e uiga lava ile tala lea. E iai foi le tala ile tuga male Tuiman’ua lava, mafuta ua atoa le masina o nonofo le tuitoga i tausi foi le Tuimanu’a meo tala I aso ia. Ua o’o loa na fai atu loa le Tuimanu’a ile Tuitoga oa lava mea uma, pule ai a? Pau a le mea nao le tasi a le mea oute fa’aaoga ina, o Vai Sā, tusa ole vai ta’ele na ole tupu o Tuimanu’a. Ae peita’i ane, ua oo ile taimi olea o ai ia Tuitoga i lana au malaga. “Na’o le taimi lava ete ta’ele ai ile vai ole taimi lena ete oti ai”. Le usitai la, ua oso atu Tuitoga ma lana au Malaga, oso atu i tafatafa ole vai, va’ai atu Tuitoga manaia le vai ile ta’ele, ia oso loa iai, ua faatamilomilo nei le au malaga a le Tuitoga a? ma usu le latou pese foi lea,” I toga e, I toga e!”
### Appendix 12 Detainee Demographics & Background

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<th>Family Groups Detention</th>
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<td>family</td>
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<tr>
<td>Detainee underwent a ‘restorative justice’ intervention</td>
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<td>⋄</td>
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<tr>
<td>family member attended the New Zealand Parole Board hearing in support of the detainee</td>
<td>⋄</td>
<td>⋄</td>
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<tr>
<td>maximum number of people in the household during home detention term (including detainee)</td>
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Table A12 Demographics A
Appendix 13  Key Informant Interviews Justice Officials - Home Detention Study

Key Informant 1 Maota

Location: Arohata Prison, Interview Room (Te Upoko o Te Ika/Wellington)
Professional Role: Prison Officer
Date: 14th June, 2006
Length of Interview: 44 minutes
Professional experience working with Samoan Prisoners (years): 15+

Profile
- Maota is a senior officer having been employed in the New Zealand Prison Service for fifteen years. In his role as Receiving Officer (RO) for the last 9 nine years his role is to register prisoners as they enter and leave the prison, and to relocate them into the prison population. He describes the unique professional contribution that Pacific prison officers make within the prison system, and explains the differences between Pacific prisoners and non-Pacific prisoners.
- Born in Tokelau; 15 yrs in Pris on service; RO 8 years
- Not many Samoans in prison
- Teaching background, secondary school, to help people esp literacy skills
- PI staff officers do so well on the ‘floor’ – a lot ‘mana and respect’ from the prisoners
- Culture – relaxed take things in their stride (colleagues climbing ladder) – pave the way; pioneering role in corrections
- Being consistent in authoritative custodial role, show humility, able to ‘stick their neck out to sort out incidents’ (conflicts with prisoners)
- Trait – stems from growing up in big families ‘older brothers to nieces and nephews and play that role in corrections’
- 3rd youngest of 8 in big family; plays a big role
- Not much difference with Sa/PI prisoners – tend to be ‘very, very respectful’, humble, remorseful
- Speaking and understand Sa language; Sa born more respectful than NZ born
- Homed suitable for certain, people who would be worse off coming into prison; family suffering more if prisoner imprisoned; some would be ‘punished’ more on homed by ‘living life more realistically, sussing out the bills day to day’; some of them are ‘so remorseful’ they don’t need to be imprisoned
- Remorsefulness for victims impt, needed ‘to move on’
- Reoffending – handed themselves in, no one at home, no supports;
- First offenders ‘mixing with experts’ – a downfall in the whole system; encourages them to go out there and reoffend ‘better’
- Study a Great idea: ‘Coping’ in home environment, levels of pressure to do better
- Culture huge part in improving rehabilitation of prisoners; reoffending rates low – anecdotally based on ‘culture’ – element of shame, shame for their families, mum and dad, let down self/family; use of maiden name, rather than family name to prevent them reoffending
- Fautua consultations
- Coping with life without crime – characteristics observed in jail: ‘confidence in self’ – family pressure of pleasing others rather than themselves as factors to commit fraud
• First offender – absolute no history of crime then suddenly seriously assault/violent offend
• PI offenders usually respectful, very compliant, until they lose their temper and 'when they go, they go'
• 'tears in the eyes' when they talk about their families
• Hunches about those who would be returning to prison 'see the huge change' when they leave – more confident, not got their head down, they look good
• Factors that work for resettlement
• CPS – more help could be given to family and better supervision while prisoner is still in control of CPS; programmes for prisoners while they’re here, if counselling helps resolve issues between family; compliance with conditions primary role of cps
• Currently better assessments
• Programme for PI prisoners – need to be ‘family orientated’, to increase ‘family involvement’ – family is the ‘backbone’ of the PI, important for prisoner rehabilitation and biggest help to stop them coming back to prison
• Case manager’s role – facilitate the connection between prisoner and family members? Probably nothing out there in the community for PI
• Returning PI prisoners back to Island homelands

Key Informant 2 Tao

• Location: Arohata Prison, Interview Room (Te Upoko o Te Ika/Wellington)
• Professional Role: Prison Officer
• Date: 14th June, 2006
• Length of Interview: 1 hour
• Professional experience working with Samoan Prisoners (years): 16+

• Depth of experience of Samoan prisoner officers working inside the prison service with Samoan offenders presents unique perspective on many issues
• 16 years in Prison service
• Preferred working in womens’ prison
• Solosolo (father), Satitoa (other)
• One of 7 kids, 3rd oldest (5 bros/2 sis fluent in language)
• Attracted to job because of money very attractive, stayed in job because of ‘variety’ specialised in various
• Punitive to now rehabilitative – too p.c now, gone full circle – seem to think ‘giving them too much, now taking things back’
• IOMS was meant to be the be all and end of crime however people coming back because things outside of the control of prisons ie family life, the connections between families (can’t break the cycle), govt targeting all areas of life esp recidivist Maori prisoners entrenched in crime life; upbringing
• Sa prisoners crime rate not as high however ‘one off’, don’t reoffend but doing ‘long terms – 5 to 15 years; they don’t come back to prison, much more serious crimes not doing 1-2 years
• Samoan prisoners mainly rape (male), fraud for female, handful of violent assaults (male gave hidings, female quiet one until male had fling and she became violent esp relationship affair)
• ‘shame’ prevented females making charges against partners, tolerate beatings from husbands but can’t tolerate affairs so they end up killing them
Young offenders crime now more serious than early 90s, serious assaults, aggrob, attempted murders vs small time fraud, shoplifting, victims unknown to them, elderly and defenceless and vulnerable

NZ born have gang links (younger gangs), Auckland Crypts, West Side, youths in cliques

Age of prisoners coming in – not 21,25 its 15, 17 yr olds doing horrendous crimes, no remorse, no respect for authority or elders,

All gang related or self-centredness, respect is for violence

Samoan prisoners – NZ born who have left their families, doing their own things; and Sa from SA who have acclimatised to way things done here, run away from parents and live on the streets

Literacy issues, reading, writing problems many not completed school; picked up through assessments – individual progs better than in groups for literacy ‘I don’t wana be known as dumb’ and don’t attend because others would see their inability to read/write

Forms of healing – Ifoga

Fraudsters – no remorse, rationalising theft because of insurance

Disciplines ‘island styles’, if you do wrong, get smack once, if do it again, ‘big hiding’

Next generation, some taught old way through culture, some not

Sentencing Home Detention – “white collar crime tends to get it, H.D politically driven, when govt stamped down on collar crime/home invasion everyone who applied for homed won’t get it”; at this time – homed slowing down, it doesn’t matter what you do, long sentence it all applies; then public outcry on reoffending, decline of homed; better assessment now with probation services/corrections/psych services all working better now than they were

Can’t recall any Samoans getting homed

Supervision probably needs to improve, checks haven’t been done often leads to poor monitoring and supervision; offending occurring outside of home ie theft doing burglaries;

Those raised in the culture ‘home is a strength’ – identifying as Samoan; this generation growing up and identifying from their peers not with home

Good questions to ask prisoners: are you strong to be out there without reoffending; strong enough to turn your mates away – if not best to turn down HomeD; safeguards of keeping away associates, link to good people; supports aren’t so good out there;

Relocation would be impt – corrections should be better able to relocate accommodation; doesn’t help if they are going back to same location; better to go somewhere they’re not known – ‘new start’;

Programmes: CPS running outside progs, budgeting, drug rehab, thinking straight

One time offender/low risk not eligible for progs because of limited funds and so miss out – including those applying for homed

Conditions – take photos ‘personal’ ‘that they can identify with rather than buildings’ to give insight to them, anyone can take a picture of a house, ‘why did you take photo’

Camera – study linked it up with purpose of photos; ‘hindsight’ will get better as you go along

Forms clear; RoC*RoI – 6mths leading up to offending; Risk of Offending – sentence planners ask these questions; assessment tool – events, substance use etc; cross check sentence plan and prisoners perspective;
• Incest – from older males to younger females as potential issue with many Sa women; good and bad about culture – pathway to womanhood, ‘touching’ sexual behaviours that occurs within families;
• Interest to find out if that was original factor for young woman leaving home in the first place – offending at the family home – it may still be unresolved; sponsor maybe be unsuitable
• Separate cameras for offender/sponsor and individual interviews/ option to be interviewed together or separate
• Husband and wife as sponsors/ where a niece returns back to the house

Key Informant 3 Unu

Location: Arohata Prison, Interview Room (Te Upoko o Te Ika/Wellington)
Professional Role: Prison Officer
Date: 14th June, 2006
Length of Interview: 50 minutes
Professional experience working with Samoan Prisoners (years): 24 weeks

• Had wanted to be police woman
• Being ‘brown’ advantageous, ‘helping women’ who have made bad choices
• Has empathy and can relate to them
• Familiarity with Samoans 'you look after your own kind', draw the lines, correctional officers they’re prisoners
• 'not to take it for granted and not falling into ways of trying to please extended family, like getting loans for fa'alavelave'
• Everything’s about ‘money’ Money between two Sa prisoners – budgeting course be good for this prisoner to do, later on homed, ‘it all comes down to money, there’s pressure there’s tension, cause hardship, poverty and all about money’
• Homed good for elderly, in respect of age, would be okay – better off at home
• Not to take it lightly, ‘healing part is so huge’ – that it’s a good healthy home with lots of support – alcohol/drug free; support for children; help for them to get to counselling
• At home, do you think you’d learn more ‘inside’ or ‘outside’; mixing with others (prisoners) is it an advantage not learning every trick in the book
• Which is better ‘the company of their own family members or associating to prisoners in prison’ – what parts of prison life do they miss? Are you yourself when you’re in or outside?
• ‘Appreciate what you’ve got’ – not because your Sa or old? ‘they should ‘earn it and value getting homed’ – home environment is not like prison – smells, noise, freedom, grateful and thankful, important to know what they have and don’t have, and to ‘look after it’ (protecting, valuing)
• Regret – is part of their turn around
• Life full of crime or without it - ‘carrot right in front of them’
• Hunches to those who are ‘remorseful’ or ‘real tears’
• Samoan/NZ born prisoners – huge difference ‘those born in Sa’ in comparison, household chores and hospitality; Appreciation and valuing what they have; prayers, living off the land; tidiness in cell, compliant and non-complaining of food; quick to say no to ‘stand-overs’; works really well,
• NZ born not appreciate so much; complaining; unaware she is demanding, testing, pushing ‘try her luck, more daring, not be herself, is a blender with the in-crowd’; doesn’t value what they have
• Clear explanation vs direct approach because of language differences;
• Minimising of crime committed, ‘misunderstanding’ from the judge
• Visualising is good, ‘that’s where I was, this is where I am now, I could end up there I better value what I go here,’ comparing the surroundings
• ‘Prison inside is Ugly’ – sounds of the keys jingling
• Sounds of prison (milk in the morning, 6am train, officers arriving in the morning by sound of car)
• Smells of prison – food; detergent smell ‘trigger’ prison experiences
• Mothers at home with their children – ‘appreciating time with them’; their child, their responsibilities
• ‘Suffering’ everyone suffers while they’re away in prison esp children; worried about children being teased because of stigma/shame of prison
• NZ born lacks bonding with her child, ‘child as a meal ticket’ – partner’s family benefiting from childcare benefit entitlements
• Saying: Proverbs 31:30 ‘Charm is deceiving, fleeting but a woman who fears the lord shall be praised’ – praying;

Key Informant 4 Pu’e

Location: Arohata Prison, Interview Room (Te Upoko o Te Ika/Wellington)
Professional Role: Prison Officer
Date: 14th June, 2006
Length of Interview: 1 hour
Professional experience working with Samoan Prisoners (years): 8 weeks

• Mental health recovery model for 5 years, coming into corrections difficult adjustment to ‘custodial’ role; transition very hard, very challenging; make a difference in peoples life; some prisoner officers have lost that purpose
• Community interagency Enhanced Community Supports compliance issues re medication and assisted support; Wharehuruhuru, forensics unit
• ‘therapeutic vs custodial model’; ‘home as place for justice’ from forensics into community:
• Samoan offenders: One example a woman (late 20s) from broken home, parents dead/separated and she was fostered to other family members, crime burglary, serious assault charges, diagnosed prior to prison with mental health
• Prisoner identified positively with Sa prisoner officers;
• Parole board – homed. Find out about front/back end, dos and donts probation officer monitors; a good option for Sa, Pac and Maori
• Serve out rest of sentence in family ‘nurtured’ in family environment; Mason Dury Whare Tapa Wha and Sa aiga Pandanus mat
• Elements of families – family environmental factors which are conducive to ‘nurturing’ – important ‘placement’ be suitable, prisoner looks at officer as a ‘big sister’
• Healthy transference
• Role of family in sentencing? Can it be achieved without living with family but in institutional/friends? Yes, officers are impt to play that role; right medication, employment and good social network of friends
• Visual Diary –‘heartens me’, ‘familiar to me’ (images are familiar, salu tuaniu, boy at church, ie toga) because all these things play huge part in my life as well; because we belong to a culture – share in common fa’aSamoa
• Study is about ‘hope too’; Sa people have ‘faith’ – ‘striking the chord’; growing up in big Sa family, religious background, not many material belongings but ‘faith and hope’ being instilled by parents
• Like to think that Sa prisoners will show things from the culture unlike other ethnic groups (maori, palagi)
• Sa prisoners – bible (searches); ‘guilty searching the bible’ – ‘felt funny’ to search bible in cell; 2 Sa prisoners are different to other ethnics
• Observed remorsefulness, “Ua la, mean a maua! do the crime do the time” – prisoner agreed, she bowed her head; establishing rapport, acknowledging that she had acknowledged her as a Sa prison officer; ongoing connection
• Ma (head bowed down) part of the remorse shown the first time they met, first day she arrived; homed really ideal for someone like her, ‘toaga’ to make it work for herself; family visit regularly; first langu
• Use of Study – private space, cell, objects in the cell
• Most Sa love taking photos; photos would give other Sa insight about prison life – would be interesting for those who don’t know about prison (my parents), safety, kinds of people in prison, ‘murderers, this that and that’
• Stigma to prison like mental health? Yes, ‘self care units’ and ‘shopping’ officers are in civilian clothing
• Riding the Train wearing Prison Officer Uniform in public – ‘stares’, ‘brown woman, but also wearing a green uniform’; ‘stigma’ in mental health adopted in Pathways empowering, deinstitutionalisation ‘eco-cars’, ‘low key’ – not overtly authoritative in public but needing to show and take control
• Interested to know about ‘family relationships’ bonding that prisoner makes on HomeD and reliance on family
• Reoffending: likened to ‘relapse’ and returning to ‘reoffending’ – sad; obstacles leading to reoffending – shortage of money (finance), being turned down for job, personal disappointments
• In mental health Good follow-up with consumers, and other networks, families; came down to individual’s motivation
• Proverb/Samoan saying: ‘Ava I lou tama ma lou tina’ – seeing parents as an adult, rather than in eyes of a child, rules instilled for purpose; discipline good thing; not just about nuclear family, but also extended family, fa’alavelave back in Samoa
• Respect others the way you want to be treated, humble yourself, but watch out if you cross me, respect your elders
• In mental health – regular supervision occurs but not in corrections; hence transition difficult (future wants to be Occupational Therapist), custodial is not for me
Appendix 14  Stories of Other Women Home Detainees

Key Informant 5 Upu

Location: Auckland (Tamaki Makaurau) Professional Role: Family Court Lawyer
Date: October 11th, 2006
Length of Interview: 21 minutes
Professional experience working with Samoan Prisoners (years): 20+

Upu discusses the benefits and disadvantages of home detention as a sentencing option for three woman clients that she advocated for as a legal representative.

Lupe

NZ born Samoan; Mother of three children on home detention for benefit fraud; approved to drop & pick kids at school during her sentence; approved to work part-time with her former employer, surveillance equipment installed at the work premises; separated from her spouse, the father of her children but on-going problems with him over the duration of her home imprisonment.

Fili

Fili, a Pakeha woman, mother of eight children to a Samoan man; she was convicted of benefit fraud and approved to be at home to complete home detention so she could care for her children. She recently separated from her spouse who was extremely violent towards her for many years and allowed to collect the children from the house under a temporary restraining and protection order.

Mina

Mina was convicted of fraud and granted home detention. She was known to many of the NGOs and government agencies in her area because she was a victim of child sexual incest where the perpetrator (Step-father) was convicted of the crime. Mina had a long history of chronic mental illness and confusion surrounded her case when she tried to claim ACC compensation while at the same declaring that she was in an intimate relationship with her Step-father. Throughout the duration of her home detention sentence, Mina was unable to get counselling and remained unemployed.