WAYFINDING:
A grounded theory about family carers learning to manage technical health procedures at home

Janet McDonald

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Abstract

Advances in medical care and technology, population ageing, policy shifts towards community care and family preferences for home over institutional settings are all contributing to increased demands on family carers. Beyond housework or personal care, some carers take responsibility for ‘technical health procedures’ ranging from changing wound dressings to managing a tracheostomy. There has been limited research about carers’ experiences with such roles or how professionals teach and support carers who manage these procedures.

The objectives of this research were to develop theory about how families learn to undertake technical health procedures and their experiences of managing these procedures at home. Grounded theory methodology was used, with data drawn from interviews with 26 family carers caring for their child (20), partner (3), parent or grandparent (3). Technical procedures included nasogastric, gastric or jejunal feeding, intravenous or subcutaneous medication, urinary catheters, bowel stoma care, tracheostomy management and peritoneal dialysis. In addition, 15 health professionals involved with teaching family carers were interviewed.

An overall theory of ‘wayfinding’ has been developed to explain the experience of carers who learn to manage technical health procedures. Wayfinding was motivated by wanting good care and a good life for the care recipient. It was an active process, utilising health professional and other sources of learning and adapting them through lived experience to unique home situations.

Wayfinding comprised two processes, the first of which was a learning journey. This had three phases: initial concentrated professional teaching; taking responsibility and continuing learning as a novice carer; and ultimately, with time and experience, becoming an expert carer. Through this process, relationships between carers and health professionals could change from learner:teacher to the mutual recognition of expertise.

Alongside the learning process, a second process of embracing care described the way family carers experienced and responded to taking on the role of managing technical health procedures. The spectrum of embracing care consisted of five positions which carers adopted and moved between, namely accepting embrace, resisting embrace, reluctant embrace, relinquishing embrace and being overwhelmed by the caring role. Two factors which influenced carers’ movements between positions on this
spectrum were whether or not they perceived the procedure benefitted their family member and the availability or absence of appropriate support for managing it.

Managing technical health procedures at home occurs in the context of family relationships and often with limited alternatives. The challenge for society and health services is to consider what level of caring should be expected of families and how carers can best be taught and supported in this important role.
Acknowledgements

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# Glossary and list of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>A&amp;E</td>
<td>Accident and emergency department</td>
</tr>
<tr>
<td>CYF</td>
<td>Child, Youth and Family (part of the Ministry of Social Development)</td>
</tr>
<tr>
<td>District nurse</td>
<td>New Zealand community nursing service</td>
</tr>
<tr>
<td>EEG</td>
<td>Electroencephalogram, a measure of the electrical activity of the brain</td>
</tr>
<tr>
<td>ENT</td>
<td>Ear, Nose and Throat specialist</td>
</tr>
<tr>
<td>Gastrostomy</td>
<td>An opening into the stomach for enteral feeding</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>HETF</td>
<td>Home enteral tube feeding</td>
</tr>
<tr>
<td>IV</td>
<td>Intravenous</td>
</tr>
<tr>
<td>MicKey button</td>
<td>A brand of enteral feeding tube</td>
</tr>
<tr>
<td>NG</td>
<td>Nasogastric tube</td>
</tr>
<tr>
<td>PEG</td>
<td>Percutaneous endoscopic gastrostomy</td>
</tr>
<tr>
<td>PEJ</td>
<td>Percutaneous endoscopic jejunostomy</td>
</tr>
<tr>
<td>Port, Portacath</td>
<td>An implanted device providing venous access</td>
</tr>
<tr>
<td>pH</td>
<td>A measure of acidity</td>
</tr>
<tr>
<td>Trache</td>
<td>Tracheostomy</td>
</tr>
<tr>
<td>UTI</td>
<td>Urinary tract infection</td>
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Chapter 1: Introduction

Caring for a family member who is ill, disabled or frail is a common life experience. Most people are likely to receive and give care within their family at some time in their life. Moreover, health and social systems are dependent on the informal support given by families (alongside some formal services) to enable many people to live at home and avoid more expensive community or hospital care. Informal care thus plays a vital role both for family units and society as a whole.

Since the 1970s, the nature and importance of family care have been increasingly recognised through research, policy development and carer advocacy groups (Heaton, 1999). This thesis adds to the caregiving literature by centring on a group of carers whose particular needs have not been well-considered to date, namely those whose care moves beyond such things as household chores or personal cares tasks to taking responsibility for ‘technical health procedures’ such as renal dialysis, nasogastric tube feeding or intravenous therapy.

This chapter begins by defining the focus and scope of the thesis. It then provides some background about informal care and in particular, what is known about New Zealand carers. The research questions that guided this study are introduced and lastly the structure of the remainder of the thesis is set out.

Terminology

The focus of this thesis is informal care, provided to a family member, which includes assistance with one or more technical health procedures. Each of these key concepts is defined below.

Informal or family care

Health and social services may be organised and provided formally (paid for either publicly or privately) or informally (and largely unremunerated). Twigg (1992) defined informal care as “…normally occur[ring] in the context of family or marital relationships, and is provided on an unpaid basis that draws on feelings of love, obligation and duty” (p. 2). However, she emphasised this did not imply such caring
was casual or easy. In contradistinction, formal care is generally paid and is framed by employment agreements, service specifications and professional regulations (National Advisory Committee on Health and Disability, 2010).

As informal care is predominantly provided by family members it is also referred to as family care which is the term used in this thesis. A small proportion of informal care is provided by friends or neighbours but they are generally not the principal carer and are likely to provide sporadic practical assistance rather than intimate care (Atkin, 1992). Although mutual support is a typical aspect of family life, informal care is recognised as going beyond the customary extent of reciprocity in these relationships (National Advisory Committee on Health and Disability, 2010).

The New Zealand Carers’ Strategy defines a carer as “anyone who supports a person with ill health, a disability, mental illness, an addiction, or in their old age” (Ministry of Social Development, 2008, p. 4), while the recently updated accompanying Action Plan states, “A carer provides care for someone close to them (family or friend) who needs help with everyday living because of a health condition or disability” (Ministry of Social Development, 2014).

Throughout this thesis, caring refers to informal family care, unless otherwise specified.

**Carers and recipients**

People who care for family members may not define themselves as family carers; they may prefer to see themselves primarily as a wife, daughter or mother, for example, and consider care an intrinsic part of that relationship (O’Connor, 2007). Referring to the person they care for as a ‘recipient’ is likewise contentious and may be interpreted as implying passivity and obscuring reciprocity within caring relationships (Nolan, Grant, & Keady, 1996). Nor are care ‘giver’ and ‘recipient’ roles always distinct – each member of a dyad may support the other (Argyle, 2001). From a disability rights perspective, concepts of care and implications of dependent recipients may be perceived as oppressive and disempowering (Morris, 1997).

Despite these recognised imperfections of the language, some terms must nevertheless be chosen to represent the topic being discussed. As this research considers the perspective of those who give care, they have been referred to as carers (or caregivers when referring to literature which used that term; carers is the more
common New Zealand usage). The ‘cared for’ have been referred to in terms of their relationship to the carer (for example, spouse or child) in a particular situation, or the generic term ‘recipient’ has been used. In literature and interviews from health professionals, the recipient is often termed ‘the patient.’ These terms are not intended to be pejorative in any way or imply there is no reciprocity of care; they simply provide convenient shorthand labels for two parties in the ensuing discussion.

Technical health procedures

This research focuses on a sub-group of family carers – those who undertake specialised care related to a health procedure such as a tracheostomy or gastrostomy. These carers are likely to refer to the specific procedure they perform, and research about a single procedure likewise uses a particular term, such as Parents’ experiences and views of caring for a child with a tracheostomy (Flynn, Carter, Bray, & Donne, 2013). However, I was interested in a range of procedures in order to compare the teaching and learning surrounding them and thus produce a grounded theory applicable to procedures generally. Therefore, a generic term that could cover a range of procedures was sought.

The initial choice of ‘medical procedures’ was quickly replaced by ‘nursing procedures’ on the assumption that while doctors might initiate some procedures (such as the surgical creation of a stoma), day-to-day management would be a nursing role, and it was this aspect that family carers would assume at home. However, nursing textbooks (e.g. L. Dougherty & Lister, 2008; Nettina, 2010; Perry & Potter, 2004), while listing many ‘nursing skills’ or ‘clinical nursing procedures’ did not provide a definition of a nursing procedure, and nursing organisations and professional bodies such as the New Zealand Nurses’ Organisation, the Nursing Council of New Zealand and the International Council of Nurses do not define specific nursing procedures either, although competence is expected within accepted scopes of practice.

As ‘nursing’ procedures were not clearly defined, several other terms used in the literature were considered as alternatives: ‘clinical procedures’, ‘complex care’ and ‘technical procedures’ (e.g. Kirk & Glendinning, 2002; Silver, 2002). ‘Clinical’ was discarded because it can carry connotations of a hospital setting and dispassionate detachment (“Clinical”, n.d.), which did not seem to fit well with family care at home. While a carer managing home ventilation for somebody with a tracheostomy would
probably call this complex and technological care, other procedures of interest (such as urinary catheterisation) might not be recognised in this way and hence potential participants could be overlooked or discount themselves from the research. In addition, other types of care which I did not want to include could be seen as complex: for example, behaviour management of a person prone to aggression or self-harm.

Finally, ‘technical health care’ was chosen, as ‘technical’ encompasses specialised knowledge or skill (“Technical” n.d.) and suggests some training is required to gain the requisite expertise. This seemed a useful way to distinguish between caring tasks which people would commonly know how to do or could get advice about from other lay people (such as doing household jobs, helping someone get dressed or making a medical appointment) and those for which they would need some initial professional instruction (such as caring for a stoma, injecting medication or perhaps even changing a dressing).

Throughout this thesis, ‘technical health procedures’ is the generic term used for the kind of procedures family carers may manage at home. In information sheets and when discussing the research, the term was followed by a list of examples, namely: renal dialysis; urinary catheterisation; intravenous therapy; injections; caring for a bowel or bladder stoma/ostomy; enteral or parenteral nutrition (e.g. nasogastric or gastrostomy tube feeding); managing a tracheostomy, ventilator or oxygen therapy; enemas or bowel washouts; wound care and dressings; and some physiotherapy procedures.

**Background to informal care**

**The concept of care**

Care for one another has always been a part of family relationships, but it was not until the 1970s that an academic interest in this topic developed, particularly by feminists interested in the disproportionate involvement of women in unpaid care work (Twigg, 1992). Subsequently, research has explored the roles and impacts of caring, and caregiving has been framed as a public health and public policy issue (Goodhead & McDonald, 2007).

Caring comprises both work and relationships (Kirkman, 2005). A number of typologies of family caring have been developed to define its components. Fisher and
Tronto (1990) viewed caring as a process with four “intertwining phases” (p. 40), namely “caring about” (attending to our environment and its influence on our wellbeing); “taking care of” (responding to what we attend to and taking responsible action); “caregiving” (undertaking caring tasks); and “care-receiving” (the responses of those who receive care).

Bowers (1987) used grounded dimensional analysis to define five categories of family caregiving by adult children for their aging parents with cognitive impairment. Nolan, Keady and Grant (1995) refined and extended Bower’s typology through several studies to produce eight dimensions of care (p. 260): “anticipatory care” (anticipating and planning for future need); “preventive care” (monitoring at a distance); “supervisory care” (more direct monitoring, such as ensuring medication is taken); “instrumental care” (hands-on work); “protective care” (temporarily denying or covering up the need for care); “preservative care” (maintaining the recipient’s self-esteem); “(re)constructive care” (assisting a person to adapt and develop new and valued roles) and “reciprocal care” (recognizing mutuality in care relationships).

Other authors have developed further variations of concepts of caring such as nine core caregiving processes (overlapping with those above) and 63 associated skills (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000) and antecedents and indicators of effective caregiver performance (Swanson et al., 1997). However, while carers are commonly recognized as helping with such things as household tasks, personal care, emotional support, supervision and safety, transport and administrative roles (e.g. Ministry of Social Development, 2008), little attention has been given to technical health procedures. Levine and her colleagues argued this was due to the common use of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) to measure caregiving tasks, but that these did not encompass the “skilled nursing care” role which has developed alongside the shift of technical health care from hospital to home (Levine, Reinhard, Feinberg, Albert, & Hart, 2003, p. 21). A hint of such tasks was apparent in a 1998 US phone survey of 1000 caregivers which found 19% changed dressings, 14% helped with equipment and 39% helped administer medications (Donelan et al., 2002; Gould, 2004).

A more recent online survey with a nationally-representative sample of 1,677 American caregivers attempted to quantify the “medical or nursing tasks” carers were performing as well as ADLs and IADLs (Reinhard, Levine, & Samis, 2012, p. 10). This found 46% performed one or more of the 18 listed medical or nursing tasks - of this
group of carers, most (78%) managed medications while 35% dealt with wound care, 32% used clinical monitors, 25% gave enemas or managed incontinence equipment and 14% managed medical equipment such as ventilators, tube feeding and home dialysis. In addition, 96% of those who managed medical or nursing tasks also assisted with ADLs or IADLs. More than half (57%) of those managing medical or nursing tasks did not feel they had had a choice about taking on these responsibilities. Medical or nursing tasks were most commonly undertaken for a parent (37%), followed by partner (28%) and other relative (23%), with 12% carried out for friends or neighbours.

The contribution and impacts of informal caring

Unpaid carers make a vital contribution to health and social care in the community which would be very costly to replace with formal services. Estimating the financial value of this work is challenging and a variety of methods and assumptions may be employed (van den Berg, Brouwer, & Koopmanschap, 2004). An Australian study estimated the 2010 economic contribution of carers in the range of AUS$6.5 billion (using an opportunity cost method) to $40.9 billion at replacement costs (Access Economics, 2005). These figures represent 0.5-3.2% of the Australian gross domestic product or 9.5-60% of the value of formal health care (Access Economics, 2005). An American study in 2011 estimated the economic value of unpaid care at US$450 billion or about 3.2% of the country’s gross domestic product (Feinberg, Reinhard, Houser, & Choula, 2011). Similarly, the replacement value of informal care in New Zealand in 2013 was estimated to be in the range of $7.3-17.6 billion, or 3.4-8.1% of gross domestic product (Grimmond, 2014).

The work of caring has been recognised as having many potential impacts on carers, including their physical and mental health, relationships within the family and more widely, financial implications and employment opportunities (Covinsky et al., 2001; Hirst, 2005; Legg, Weir, Langhorne, Smith, & Stott, 2013; Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2005; Nepal, Brown, Ranmuthugala, & Percival, 2009; Trivedi et al., 2014; Vitaliano, Young, & Zhang, 2004; Vitaliano, Zhang, & Scanlan, 2003). While many of these impacts are negative and have been framed as caregiver ‘burdens’, latterly attention has also been paid to the positives of caring, including enrichment in the caring relationship and a sense of satisfaction about the caring role.
Caring has also been framed as a public health issue and an ethical issue. Considering the health and needs of carers will benefit not only them but also the recipient, because of the intertwined relationship between them (Talley & Crews, 2007). Questions of justice challenge societies to consider what care should be expected of families, which family members should be expected to care (with particular attention to gender equity issues) and what state and health services supports should be provided (Arras, 1995; Levine, 1999a; Palm, 2013; World Health Organization, 2002). Dow and McDonald argued the shift from hospital to home-based rehabilitation relied on expectations that family members would pick up care, yet “this unwritten obligation carries no reciprocal rights and constitutes an invisible contract between informal carers and the state” (Dow & McDonald, 2007, p. 194). Many countries have developed public policy in response to this increasing awareness and concern about family care (Montgomery & Feinberg, 2003), including New Zealand.

**Historical developments in community and family care**

Care of the sick and disabled in early colonial New Zealand was the preserve of the family, sometimes with the support of charitable aid (Tennant, 1996). A small number of benevolent institutions for the ill, disabled and destitute began from the 1860s along with state provision of care for the mentally ill, with moves to greater institutional care over the next 100 years (Sullivan, 1995; Tennant, 1996). As medical knowledge and technology evolved, hospitals became more attractive places to seek a cure rather than await death, while other institutions kept people referred to as ‘incurables’ and ‘defectives’ out of sight (Royal Commission on Social Policy, 1988; Sullivan, 1995; Tennant, 1996).

At the same time, families have always continued to provide care (Robins, 2002). International estimates suggest informal carers (predominantly women) provide 65-80% of long-term care (Montgomery & Feinberg, 2003). In many countries, social mores encourage family care at home and there may be limited government funding for any alternatives (Parmar, Baltej, & Vaidyanathan, 1993; Sahar, Courtney, & Edwards, 2003). However, in the Western world, care in the community rather than in hospitals
or other institutions has been increasing since about the 1970s. Factors contributing to this move have included:

- advances in medical technology which enable more premature babies and those born with congenital impairments to survive, though often needing ongoing medical support; improvement in treatments and prognosis for children with chronic conditions
- development of medical equipment for home use and suitable home environments (including electricity, phones and fridges)
- concern about the psychological and social effects of hospitalisation on children and an emphasis on keeping children with their families; preference of other patient groups for home care too
- increasing longevity of the population, particularly the ‘oldest old’ in both absolute and relative terms
- rising health care costs and funding constraints leading to the search for more cost-effective alternatives to long hospital stays; more day surgery and shorter hospital stays; and the development of primary health care and community services
- closure of institutions for disabled people and the growth of privately funded or only partially state-subsidised long-term residential care options for frail older people (in the New Zealand context) (Bakewell Sachs & Porth, 1995; Kirk, 1998; Marks, 1991; Teare, 2008; Williams, Spalding, Deber, & McKeever, 2005; Wong, 1999).

In the United States, health funding changes in the 1980s including prospective pricing for hospital admissions (a set payment depending on diagnosis, which encouraged cost containment and early discharge when possible), along with removal of some restrictions to funding hospital-level care at home and the inclusion of home care in health insurance, all provided incentives for increased home and community care (Bentur, 2001; Hotaling, Zablocki, & Madgy, 1995; Marks, 1991; US Congress, 1987).

In Britain, moves to care in the community initially focused on care located in the community, but with public provision; however, changes in social policy in the 1980s marked a shift from care ‘in’ to care ‘by’ the community, with increased emphasis on care provision by the informal sector (Horden & Smith, 1998). Thus
Walker (1986) noted the ambiguity of the term ‘community care’ and that provision by ‘the community’ generally meant ‘the family’ and in particular, women.

In addition to the move to more care in the community, the type of care being undertaken by families has become more complex and of longer duration (Baider, 2011; Given, Given, & Kozachik, 2001).

New Zealand has followed these trends towards community care, with deinstitutionalisation and greater emphasis on the community provision of health and disability support services gathering pace from the 1970s (Horsburgh, Smith, & Kivell, 2002; Kirkman, 2005; Ministry of Health, 2003; National Advisory Committee on Health and Disability, 2010; Office for Disability Issues, 2005; Walmisley, 2003). The Disabled Persons Community Welfare Act 1975 reflected and strengthened the developing momentum for disabled people to live and work in the community, and provided funding for a variety of community support services for disabled people and their families.

The emphasis on community care continues to be apparent in current New Zealand health and disability policy. For example, the New Zealand Health Strategy has an objective of “Support[ing] policies and programmes that enable people to be cared for in the community” as part of achieving its fifth goal of “healthy communities, families and individuals” (King, 2000, p. 11). The third principle of the Child Health Strategy is that “Child health and disability support services should be available as close to home as possible, within the bounds of quality and safety”, so in developing health services for children, “emphasis should be placed on community-based or outreach services wherever possible and appropriate” (Ministry of Health, 1998, p. 18). The Health of Older People Strategy encourages the development of health and disability services which support ‘ageing in place’ – “offering people the opportunity to continue to live safely in their community” (Ministry of Health, 2002, p. 3). Finally, objective 8 of The New Zealand Disability Strategy is “Support quality living in the community for disabled people” (Minister for Disability Issues, 2001, p. 12).

In addition, He Korowai Oranga Māori Health Strategy and the government’s Whānau Ora policy (King & Turia, 2002; Te Puni Kōkiri, 2013) emphasise the health and wellbeing of the whole whānau/family rather than individual members separately. This approach is also relevant for caring in families – although some services or policies may specifically address ‘carers’ or ‘care recipients’, the needs of each are intertwined and linked with those of the whole family. An holistic view of health and
the importance of the whole family are also reflected in the health plan for Pacific peoples, ‘Ala mo’ui (Minister of Health & Minister of Pacific Island Affairs, 2010).

In 2008, The New Zealand Carers’ Strategy and Five-year Action Plan was published and subsequently updated in 2014 (Ministry of Social Development, 2008, 2014). These were developed through a partnership between government and the New Zealand Carers Alliance (a peak body of more than 40 not-for-profit organisations which include carers’ interests) and in consultation with carers and the general community (Ministry of Social Development, 2008). One driver for developing the strategy was recognition that New Zealand’s ageing population will increase the demand for family caring, along with an emphasis on increasing choices for carers to enable them to combine both paid employment and caring responsibilities (Ministry of Social Development, 2008). Four of the five objectives in the initial action plan were retained in its revision (respite services, protecting carers’ health, providing information and improving pathways to paid employment for carers); the fifth, “Provide financial support for carers” (Ministry of Social Development, 2008, p. 25) has been replaced by “Increase understanding and awareness of the carer’s role” (Ministry of Social Development, 2014, p. 24).

The issue of whether family carers should be paid has been highlighted in two recent court cases. A group of parents caring for adult disabled children won a Human Rights Review Tribunal case in 2010 against the Ministry of Health policy of refusing payment to family carers because they were expected to provide free, natural support (Atkinson and others v Ministry of Health, 2010). Subsequently the government amended the New Zealand Public Health and Disability Act 2000 to allow some payment, while “affirm[ing] the principle that, in the context of the funding of support services, families generally have primary responsibility for the well-being of their family members” (§70A(1)). The Ministry of Health then developed a new Funded Family Care Operational Policy (Ministry of Health, 2013). However, payment for family carers under this policy excludes spouses and is limited to those caring for disabled adults with high or very high needs otherwise requiring residential care (as determined by a Needs Assessment and Service Coordination agency). The policy was expected to apply to approximately 1600 carers (Ryall, 2013).

Similarly, a group of family carers recently won a case allowing them to request back pay from the Accident Compensation Corporation (ACC) for unpaid attendant care provided prior to 1992 (ACC v Algie, 2014), but ACC has appealed the court’s
decision. It should be noted that changes to ACC legislation from 1992 allowed family members to be paid for attendant care, and this was an argument for also changing the Ministry of Health policy above. However, in deciding how much attendant care an ACC claimant is entitled to, ACC must consider “the extent to which household family members or other family members might reasonably be expected to provide attendant care for the claimant” (Accident Compensation Act 2001, §Schedule 1, 14(d)) and family members may be paid at a lower rate than non-family carers.

At this point, an explanation of some important features of the New Zealand health and disability system is necessary. The next section provides a brief overview as context for this research.

**The New Zealand health system**

New Zealand health services are largely publicly financed (about 83%) with the remainder funded by user payments (particularly in primary health care and for pharmaceuticals) and private insurance (Cumming et al., 2013). The Ministry of Health funds 20 District Health Boards (DHBs) through a population-based funding formula. The DHBs are then responsible for planning and funding health care which may be provided through their own services as well as through contracted private and non-governmental providers.

Since 1974, the Accident Compensation Corporation has funded treatment, rehabilitation and compensation for accident-related injuries and disability. ACC is a comprehensive, no-fault social insurance scheme funded through levies and general taxation (Cumming et al., 2013). Variations in services between different DHBs and between Health versus ACC-funded services are well recognised and raise concerns about equity of service provision (Cumming et al., 2013).

Disability support services for people whose disability is not the result of an accident are funded by the Ministry of Health based on needs assessment processes. Services for disabled people aged under 65 years are funded directly by the Ministry of Health while those for over-65s are the responsibility of DHBs (Cumming et al., 2013). Disability support may include help with personal care, household management (free
only for people with a Community Services Card\(^1\), community day services, respite
and carer support services (Ministry of Health, 2014c). Services are largely provided
through contracted agencies, but since 2010 (following a pilot running from 2003),
disabled people and their families have been able to choose to manage their allocated
funding for home and community support services through an Individualised Funding
(IF) allocation (Ministry of Health, 2010a, 2012). This approach is being extended
through a ‘new model’ offering greater choice and control of disability support services
which is currently being trialled in several areas (Ministry of Health, 2014b). A needs
assessment process is also required to access long-term residential care services, for
which a means-tested Residential Care Subsidy is available (Ministry of Health,
2014a).

In relation to technical health procedures, many services are located in
secondary or tertiary health settings. Community-based nursing services (known as
district nurses in New Zealand) provide an episodic service rather than full-time
nursing in the home; thus they rely on additional self-management by the patient or
informal care. Some ACC clients with sufficiently high levels of need may receive
some in-home nursing care. Technical health procedures may also be managed by staff
in residential settings.

**Research about carers in New Zealand**

While countries such as the United States, Britain and Australia have conducted
national surveys of carers (Australian Bureau of Statistics, 2014; National Alliance for
Caregiving in collaboration with AARP [sic], 2009; NHS Information Centre, 2010),
New Zealand has little information about the number, roles and experiences of carers.
Since 1995, the New Zealand Census has included a question about unpaid work done
in the four weeks preceding the census. In 2006 (the most recent census from which
these data are available), two of the response options were “looked after a member of
my household who is ill or has a disability” and “helped someone who is ill or has a
disability (who does NOT live in my household)” (Statistics New Zealand, 2006, Q46).
From this question alone, we do not know whether the caring was temporary or

\(^1\) A Community Services Card entitles the holder to assistance with some health care costs. The card is
available to individuals and families on a benefit or low income. See
ongoing, the nature of the relationship between carer and recipient, what types of help were being given or the amount of time spent on this activity. However, 7.8% of the total population said they looked after a member of their own household who was ill or disabled (9.1% of females and 6.3% of males) and 9.1% helped someone living outside their household (11.5% of females and 6.5% of males) (Statistics New Zealand, n.d.-a). In both cases, about two-thirds of those who said they cared were female; Māori and Pacific people were more likely to care than New Zealand Europeans; more carers were unemployed or employed part-time than in full-time employment; and the peak age for caring was 40-44 years for in-home care and 50-59 for out-of-home care (Statistics New Zealand, n.d.-a). These findings were similar to statistics collected in the 2001 Census (Statistics New Zealand, 2003).

Two Time Use Surveys have been conducted in New Zealand with nationally-representative samples, the first in 1998/99 and more recently in 2009/10 (Statistics New Zealand, 2001, n.d.-c). Participants were individuals aged 12 and over living in private households who completed a survey and kept a 48-hour diary of their daily activities, including paid and unpaid work, household tasks, caring and leisure (Statistics New Zealand, 2001). In 2009/10, an estimated 4.9% of the population had looked after a person in their own household aged 14 or older, with an illness or disability, within the four-week reference period (4.6% of males and 5.2% of females), while 8.3% had looked after someone in another household, of any age, with an illness or disability (5.1% of males and 11.3% of females) (E. Volkova, Statistics New Zealand, personal communication, March 3, 2012). The results for ‘other household’ care were similar to those in 1998/99 (Statistics New Zealand, n.d.-b), but the ‘own household’ data cannot be compared because of questionnaire differences (T. Gardner, Statistics New Zealand, personal communication, March 3, 2013).

Following the 1995, 2001 and 2006 censuses, national samples of disabled people took part in further surveys which included questions about the informal care they received (Office for Disability Issues and Statistics New Zealand, 2009; Statistics New Zealand, 1998, 2002, 2007). It is important to note participants in these surveys had a self-reported, long-term condition (lasting six months or more) and their informal carers were not questioned directly (except in the case of parents answering the survey on behalf of children), so the results are not directly comparable with the Census data (Office for Disability Issues and Statistics New Zealand, 2009). However, they do provide some further information about informal care in New Zealand. In the most
recent (2006) survey, 96% of disabled people were living in households (the remainder lived in residential facilities). Of disabled adults in households, 25% were getting help with one or more of six types of helping activities: meal preparation, shopping, everyday housework, heavy household work (e.g. gardening), looking after finances and “personal care such as bathing, dressing, taking medication” (Office for Disability Issues and Statistics New Zealand, 2009, p. 17). Care with any activity was more likely to be provided by informal than formal carers – 69% received help from informal carers and 53% from informal carers only. Getting help from informal carers was more common for Pacific disabled adults (37%) than Māori or New Zealand European (25%) or Asian/other disabled adults (21%). Care was most often given by a spouse or partner (or another family member; care from friends, neighbours or flatmates was uncommon). Helping with technical health procedures was not specified, and might or might not have been counted under personal care, with which 5% of disabled adults received help from informal carers. Of those helped with personal care by informal carers, an estimated 18% or 4,400 disabled adults received such care 24 hours a day.

These surveys provide only a thumbnail sketch of New Zealand carers, and there is limited other New Zealand research on this topic (Goodhead & McDonald, 2007), particularly the aspect of technical health procedures. In the next chapter we will therefore move to a wider review of existing literature on this topic.

**Research questions**

While there is a growing body of literature about the experience and impact of caring, there has been little attention given to the specific role of managing technical health procedures. Therefore this research sought to investigate what it is like for carers who have this role and how they learn to manage procedures which are usually the preserve of health professionals. A qualitative approach was appropriate for an initial, exploratory study. Two questions have guided this research, namely:

1. What are the experiences of family carers who undertake ‘technical health procedures’ at home?
2. How do professionals teach family members the necessary skills for such procedures, and what is the process of learning from carers’ perspectives?
Structure of this thesis

Having set the scene in this introduction, chapter two will provide a literature review about carers learning about managing technical health procedures. Chapter three explains the methodology used in this study, both from a theoretical perspective and as applied in this research. Chapter four presents the overall grounded theory of ‘wayfinding’ that has been developed, along with its component processes of learning to manage a technical health procedure (beginning with initial training then moving from novice to expert carer) and the experience of embracing care. The implications of the findings are discussed in chapter five and related to existing literature and the argument of the thesis is brought to a close.
Chapter 2: Literature review

This chapter reviews the literature relating to carers managing technical health procedures in order to provide a background for this study and identify gaps in research to date. Given the extensive existing body of work about family care, the approach and focus of this review are first explained. The findings then begin with the experiences of carers and the process of learning to manage procedures from their perspective, followed by an examination of the way health professionals have presented their teaching of technical health procedures. Three further topics of relevance are considered: issues that arise at the interface of professional and lay care, including defining boundaries and responsibilities; the concept of the expert carer; and relationships between carers and health professionals. The chapter concludes by highlighting gaps that need to be addressed.

Approach

There is a large literature on family caring. For instance, searching MEDLINE or CINAHL using ‘carer or caregiver’ as keywords, each produces around 15,000 results. In addition, the term may refer to formal as well as informal care, and to general childcare within families or early childhood education settings. A focused literature search was clearly required and was guided by the interest of this thesis on informal care involving technical health procedures and the processes of learning or teaching these. However, a further difficulty was that ‘technical health procedures’ was not a recognised keyword and it was intended to encompass multiple procedures. For this reason, it was not possible to undertake a systematic review; rather, this chapter provides a narrative overview of the literature.

From a few articles that sparked initial interest, early exploratory searching involved following references from those articles and searching further using keywords by which the articles had been indexed. A more thorough search was then undertaken with the advice of a medical librarian, using a search strategy which combined three groups of concepts:

a) Concepts related to carers: carer or caregiver or parent or parent participation.

b) Concepts related to home care and technical procedures: home care or home care services or home nursing or home treatment or nursing interventions or
nursing procedures or hospital at home or medical technology or medical device or technology-dependent children or medically fragile children or complex care or technological home care or tracheostomy or artificial respiration or urinary catheterisation or clean intermittent catheterisation or intravenous therapy or venous access devices or injections or home dialysis or wound care or dressings or ulcers or pressure sores or home enteral nutrition or total parenteral nutrition or enemas or physiotherapy.

c) Concepts related to teaching or learning: education or parent education or training or professional support or parent professional partnership.

Nursing, health sciences and social science databases (Medline, CINAHL, Scopus, Cochrane Review and Google Scholar) were searched using the terms above as keywords or the appropriate MeSH terms where relevant. New Zealand information was specifically sought through searches of the National Library’s New Zealand Libraries’ Catalogue and nzresearch.org.nz (a database of research from tertiary institutions). Searches were limited to English language material but no date restrictions were used. Searches a, b and c were run individually then combined. The best results came from combining a+b+c, but I also sifted through the broader a+b and a+c results for further relevant material. Initial searching was done in 2011 and updated in 2014.

Articles were included based on their relevance to the thesis topic (technical health care by family carers). Carers were family members (informal carers); formal/professional carers were excluded. Care recipients were any family members (i.e. both children and adults were included). Any technical health procedures were of interest (as listed under search strategy (b) above).

Only two articles were found prior to 1980; about 10% were published in the 1980s, about 25% in the 1990s and the remainder since 2000. About 40% of the collected literature was from the United States and a further 30% from the United Kingdom. The remainder was made up of studies from 17 other countries, including six from New Zealand, although these had limited detail about the aspect of learning technical health procedures (Foliaki, Nosa, Birkenhead, Kanongata’a, & Fa’amoe, 2009; Henry, 2004, 2008; Horsburgh, Trenholme, & Huckle, 2002; McNamara, Dickinson, & Byrnes, 2009; Tucker, 2004; Welman, 2007).

Half the articles explored the perspective of carers (predominantly parents), about 40% were written from the viewpoint of health professionals (largely nurses
and/or doctors), with a little under 10% considering both health professional and carer opinions. The literature from professional perspectives focused on descriptions of training programmes and education materials. About three quarters of the literature about carers came from interviews or focus groups with small numbers of participants (often using a general qualitative approach and thematic analysis or less commonly, a specific qualitative methodology such as ethnography, phenomenology or grounded theory). The remainder was data collected through questionnaires. Only two randomised controlled trials were found, one comparing conventional training with a special training programme for carers of stroke patients (Kalra et al., 2004) and the second comparing the confidence of carers giving subcutaneous medication which had been prepared by a nurse, a pharmacist or the carers themselves (Healy, Israel, Charles, & Reymond, 2011).

The earliest paper retrieved (Merrow & Johnson, 1968) reported on a 30-item questionnaire which had been used to compare the views of 50 mothers and 50 nurses with regard to the role of mothers in caring for their hospitalised child. Both parties agreed mothers wanted to undress their child at admission and to comfort, bottle feed, bathe, change and entertain the child. They also agreed mothers did not want to give injections or take a child’s blood pressure. However, where there were differences between the two groups (nine items such as “feed or bathe the child with IV fluids”, “watch rate of IV fluid” or “give enema”), mothers generally wanted to do more than the nurses thought they would want to do (Merrow & Johnson, 1968, p. 156). Algren (1985) later repeated a similar questionnaire with 20 parents, finding all wanted to feed and change their child but none wanted to change dressings, do tube-feeding, or watch the infusion rate of intravenous fluids, believing these were nursing roles. By the 1990s, greater parental participation in care was becoming apparent, though without clarity as to how parents could or should partner with nurses (Coyne, 1995; Darbyshire, 1993, 1994). A systematic review of parental participation in the care of their hospitalised children from 1994-2006 (Power & Franck, 2008) found parents wanted and expected to be involved in their child’s basic care, but in addition, some were now taking on what were traditionally nursing roles, such as giving medication and monitoring vital signs and fluid balance. Parents who were caring for technology-dependent children at home were found to continue managing complex care even when the child was hospitalised (Heaton, Noyes, Sloper, & Shah, 2005).
Although the search strategy aimed to focus on material related to technical health procedures and the learning or teaching of these, studies were often more broadly focused with limited detail about my specific area of interest. Additionally, searches produced many studies about formal rather than informal care. In particular, I initially read some research about ‘hospital at home.’ This phrase refers to the provision of a medical service in a patient’s home (Bentur, 2001). Active treatment is provided by health care professionals for a limited time and if this were not available, the patient would otherwise remain in an acute hospital setting (Fraser, 2003; Shepperd et al., 2010). Hospital at home originated in France in 1961 to provide terminal care, but has extended to many other types of medical and surgical care, and is referred to by a variety of other terms, including hospital in the home, home hospitalisation, extra-mural hospital, hospital without walls, medical home care or community nursing service (Bentur, 2001; Corrado, 2001; Fraser, 2003). As hospital at home is not about family care, literature on that topic has not been included in this review. However, it should be noted that hospital in the home services may still assume and rely on family carers providing supplementary care (Dow & McDonald, 2007) and they may shift financial costs onto the family (Bentur, 2001; Fraser, 2003).

**Carers managing technical health procedures at home**

Little material was found which focused specifically on carers learning to manage a technical health procedure at home. However, technical care is not carried out in isolation, so this section briefly considers the broader experience of caring, including the question of choice about taking on the role. Literature about the learning process for carers managing procedures is then discussed.

**The experience of caring**

Many studies have reported possible impacts of caring on carers’ physical and mental health, family relationships, work and financial status, and social life (Goodhead & McDonald, 2007). A meta-analysis of 23 studies comparing 1,594 carers of people with dementia with 1,478 demographically-similar non-carers found the carers had a 9% greater risk of health problems, 23% higher levels of stress hormones and a 15% lower level of antibody responses (Vitaliano et al., 2004; Vitaliano et al., 2003).
Another large study utilised data from about 10,000 adults in the British Household Panel Survey over 10 years to investigate transitions into and out of caring and compare the psychological distress of carers with non-carers (Hirst, 2004, 2005). This demonstrated a gradient of increasing distress with increasing hours of caring; those providing 20 or more hours a week of caring had double the risk of psychological distress compared with non-carers (Hirst, 2005). Informal carers make a significant economic contribution and save considerable expenditure on formal care; at the same time, they may face financial stress through reduction or loss of paid income along with increased costs (Access Economics, 2005; Nepal et al., 2009). Caring can lead to changes in family life and social activities and social isolation may result (Magliano et al., 2005; Petrus & Wing-Chung, 2006).

Carer support needs identified in the literature include recognition, information, emotional support, practical assistance, financial help, respite care, access to services and service coordination (Goodhead & McDonald, 2005; Kirk & Glendinning, 2002; Limbrick-Spencer, 2000; National Health Committee, 1998). New Zealand studies of Māori carers highlight the need for cultural support too (Henry, 2004, 2008; Nikora, Karapu, Hickey, & Te Awekotuku, 2004). Unfortunately, many carers have reported difficulty accessing support and services which are often described as fragmented, uncoordinated and inflexible (Disability Support Services Directorate, 2009; National Advisory Committee on Health and Disability, 2010).

A survey of 177 parents of a child with an intellectual disability and complex needs documented an astonishing average use of 22 pieces of equipment by each child, ranging from nappies (used by 95% of the children, although a third of them were over 5 years old) to a ventilator (Nicholl, Doyle, Moran, & Guilfoyle, 2013). Whilst the study did not explore the effect on families of this equipment, the authors commented that “it was evident that this has implications for storage, resourcing and resupply, as well as the technical skills required to use some of the more complex equipment” (Nicholl et al., 2013, p. 234).

Although not focused on the process of learning to manage technical health care, some studies have nevertheless included carers who might be doing such tasks and thus give an insight into their experiences. Nuutila and Salanterä’s (2006) study of the experiences of 11 parents of children diagnosed with a long-term physical illness described three phases in learning to care for their child: the time around diagnosis (including shock and emotional upheaval), learning about the child’s daily care
(including initial anxiety, a sense of incompetence and the need to adapt family life), and finally, successfully coping with care (having a sense of expertise along with increased responsibility).

A phenomenographic study, conducted through interviews with 17 carers of ventilator-dependent children living at home, provided seven descriptions of the participants’ collective experience and understanding of their caregiving (Wang & Barnard, 2008). These were “hospital is another world to me” (during the child’s initial hospitalisation); “it’s a new world” (experiencing change at home when the child is discharged); “an ambiguous social identity” (as both parent and medical carer); “the medical technology associated with my child is frightening but necessary”; “the difficulty is having the carers at home” (the necessity yet intrusion of home nursing services); “social isolation”; and “the experience as changing a person” (caregivers finding positive meanings in their experiences) (Wang & Barnard, 2008, p. 503).

A phenomenological study of 17 mothers caring for a child with a life-limiting condition described eight dimensions of caring: “caregiving, constant instability, constant observation, constant communication, a ‘no choice’ situation, knowingness in mothers, unknowingness in others, and paperwork and administration” (Nicholl & Begley, 2012, p. 645). Caregiving in turn comprised four components: “normal mothering”; “technical caregiving” (including monitoring and treatment, and organising supplies and services); “pre-emptive caregiving” (being aware of contingencies and planning ahead); and “individualized caregiving” utilising their unique knowledge about the child (Nicholl & Begley, 2012, pp. 645-647).

A hermeneutical study with 11 relatives living with an adult who was self-managing long-term oxygen or renal dialysis at home described the main interpretation of the study as “rhythmic patterns of connectedness versus separation, and of sorrow versus reconciliation” (Fex, Flensner, Ek, & Söderhamn, 2011, p. 336); that is, both closeness to and distance from the chronically ill family member and both grieving about changed circumstances alongside adjusting to the new situation. The relatives in this study were not primary carers as the patients had been taught to self-manage; nevertheless, these relatives had also learnt about managing the technology through watching health professional-patient teaching and by observing the patient’s own management. Some had deliberately chosen not to be involved with any technical care, while others gave both practical and clinical assistance (for instance, carrying equipment or suctioning a tracheostomy tube). In some cases, initial self-management
was not able to continue and care transferred to a family member (Fex et al., 2011). This study highlights that ‘self’-management may include carer support or progress to care by a family member.

An analysis of interviews with 21 carers assisting a family member requiring ventilation at home described five themes: “sense of duty; restriction of day-to-day life; physical and emotional burden; training and education; the need for more paid support” (R. Evans, Catapano, Brooks, Goldstein, & Avendano, 2012, p. 375). All but two carers said their training to manage the home ventilation had been extremely good, but most commented on the lack of ongoing support at home, despite being given a 24-hour phone number they could call. Most of the carers noted the transition from hospital to home was a difficult time but caring became easier with experience.

In a New Zealand study, researchers interviewed 20 elderly Pacific people (from six ethnic groups) caring for a young person with an illness or disability (Foliaki et al., 2009). The children’s conditions included asthma, autism, epilepsy, cerebral palsy and Down syndrome. The researchers described the carers as being very resilient yet also a very vulnerable group who experienced poverty, poor housing, significant health problems and social isolation. The children being cared for had complex medical problems but the carers’ knowledge and understanding of the children’s health needs was generally poor. In addition, the carers were often confused about the roles of different health and social service professionals and agencies, had problems accessing services and were not aware of their entitlements. The researchers considered the carers’ vulnerability and lack of knowledge posed potential risks for the children they cared for; at the same time, there was evidence the elderly people’s commitment to caring was impacting on their own health.

Two literature reviews of families’ experiences of caring for technology-dependent children at home identified a number of physical, emotional, social and financial stresses for the families (Kirk, 1998; Wang & Barnard, 2004). Support services varied in availability and staff capability, could be fragmented and uncoordinated, and respite options were limited. Ensuring the children’s educational needs were met could be difficult. Parents also reported a lack of information and training for their caring role and sometimes parent-professional relationships were conflicted with issues around power, control and trust as parents took responsibility for their children’s complex needs yet were still expected to defer to professionals.
A further literature review entitled *The impact of technology dependence on children and their families* (Mesman, Kuo, Carroll, & Ward, 2013) framed such care as burdensome and outlined only negative emotional and social effects. Other than briefly mentioning limited information as a potential stressor for parents, training needs were not reported or addressed in the paper’s recommendations which instead advised increased clinical and social support for families. In contrast, interviews with six Japanese parents providing home parenteral nutrition for their children focused on their positive experiences and categorised these using a resilience model (“I am” – inner strengths; “I can” – skills for dealing with difficulties; and “I have” – external supports) (Kawakami & Fujiwara, 2013, p. 614).

Resch et al. (2010) conducted seven focus groups with a total of 40 parents of children with disabilities, asking them about the stresses and challenges of caring and the supports and services they needed. Four major factors that influenced the parents’ wellbeing emerged through content analysis of the data: access to information and services, financial barriers, school and community inclusion, and family support. The researchers considered “these results indicate that parent stress and wellbeing is also associated with a lack of match between their needs and the information, resources, and support to respond effectively to those needs” (Resch et al., 2010, p. 147). Therefore, rather than viewing disability as a personal problem, they advocated a social model which would consider the environmental supports these parents and families needed and they called for more family-centred policies and interventions.

**Choosing to care**

Discussing the ethical and social implications of high-technology home care, Arras and Dubler have argued that family members may have little choice in taking on a caring role (including technical health care) for a relative at home (Arras, 1995; Arras & Dubler, 1994). This is the result of few alternatives, expectations that family members should care for one another and a lack of information about the implications of accepting the role (Arras, 1995; Arras & Dubler, 1994).

Kirk and Glendinning conducted in-depth interviews with the parents of 24 technology-dependent children and 44 health, social care and other professionals to explore the families’ experiences of caring at home, their needs for support and how those needs were being met (Kirk, 2001; Kirk & Glendinning, 1998, 2000, 2004).
Parents said they felt that they had little choice about taking on a technological caring role. This lack of choice related to their sense that professionals assumed rather than negotiated their involvement, their sense of obligation to care for the child, their desire to have the child at home (both to improve the child’s quality of life and to lessen the disruption to family life of hospitalisation), and the practical necessity of parental care if the child were to be discharged from hospital, given what alternative health and social services were available. Professionals interviewed in this study expressed concern that parents did not have a choice about taking on responsibility for clinical procedures. “They felt that the philosophy of parent participation in the care of hospitalized children (and professional expectations) led parents to become involved in care-giving prior to discharge. It was then unquestioningly accepted by hospital staff that they would continue to care for their child following discharge home” (Kirk, 2001, p. 597). Professionals confirmed these children could not be discharged unless their parents cared for them, and some community nurses felt that hospitals exploited parents’ sense of obligation in order to discharge the child (Kirk & Glendinning, 2000).

However, parental acceptance of their roles was not static and once home, they were more assertive about negotiating additional responsibilities with professionals (though this was not easy), evaluating whether or not it was appropriate to do more according to whether they perceived this was in the child’s and family’s best interests (Kirk, 2001; Kirk & Glendinning, 2000). Many of the professionals in this study considered there were theoretically no limits to the types of clinical procedures parents could perform, but they were influenced in individual cases by their perception of what the parents could cope with and whether they considered the home environment suitable (Kirk, 2001).

Other authors have also noted assumptions, a lack of choice and limited negotiation as to whether families will take on care, within both hospital and community settings (Brett, 2002; Corlett & Twycross, 2006; Darbyshire, 1994; Israel, Reymond, Slade, Menadue, & Charles, 2008; Royal College of Paediatrics and Child Health, 1997). While, as noted above, carers may later resist taking on additional tasks, they may also become more willing over time. For instance, Khair (2003), a nutrition nurse specialist, noted some carers were willing to learn to feed a child through a nasogastric tube but did not initially want to reinsert the tube if it came out; later, they might choose to learn how to do this at home. However, this ‘choice’ was made in the context of otherwise needing to wait for a community nurse or go to the hospital to
have the nasogastric tube replaced, with the child meanwhile not able to be fed (Khair, 2003).

In their studies of parents caring for technology-dependent children, Kirk (2001) along with Reeves, Timmons and Dampier (2006) have reported limited negotiation with parents about care responsibilities when their children were readmitted to hospital. Even in this setting, staffed with professional nurses, parents were simply expected to continue caring; at the same time, their autonomy could be restricted, such as in administering medication (Reeves et al., 2006).

While it seems many carers may not consider they have any real choice about managing a technical health procedure, two studies about home palliative care have reflected a more positive choice by carers to take on this role. In a study which interviewed 17 parents who had cared for their dying child within the last five years, the authors claimed, “Parents readily took on aspects of care for their child that would traditionally be performed by nurses, eg maintaining intravenous infusions, giving injections etc.” (Darbyshire, Haller, & Fleming, 1997, p. 3) However, reasons given for this were that parents believed they had to acquire these skills if their children were to continue to be cared for at home (given the limited availability of community nursing services) and sometimes because of a lack of confidence in community nurses’ knowledge and skills about children and paediatric palliative care (Darbyshire et al., 1997). In Anderson and Kralik’s study (2008), 14 carers were interviewed about their experiences of administering pre-prepared palliative medication to their spouse or child through an in-situ subcutaneous butterfly or cannula. The authors reported that “The carers willingly assumed the responsibility of medication administration, as it allowed the clients to remain at home where they desired to be” (B. A. Anderson & Kralik, 2008, p. 349). It also meant carers could provide immediate relief for their loved one’s pain and other symptoms, which gave them a sense of control and empowerment. Carers had access to 24-hour telephone advice and this support was highly valued. Carers reported some initial anxiety about injecting medications, but this decreased as their confidence grew and it “became a routine part of everyday life” (B. A. Anderson & Kralik, 2008, p. 352).

The more positive choice of these carers to take on complex roles could reflect the expectation that it would be for a limited duration in a palliative care situation. Conversely carers for those with chronic conditions could find themselves in this role for many years with little alternative.
Learning to manage technical health procedures

There was little literature specifically about how carers learnt to manage particular technical health procedures at home. This section begins by discussing six studies which provided some detail about carers’ training experiences, then highlights several recurring themes from the literature before summarising what may help or hinder carers’ learning.

An early Canadian study interviewed 44 parents of children who had been discharged home between 1977 and 1984 on continuous oxygen therapy and 20 professionals involved with these children (Young, Creighton, & Sauve, 1988). Most parents (35) felt hospital staff had adequately prepared them to manage their children’s care and equipment at home but felt less prepared to deal with emergencies, with 12 stating cardiopulmonary resuscitation training was rushed or absent. Twenty reported that community resources for families with children on home oxygen were inadequate and community health nurses’ knowledge was often poor; in contrast, the availability and support of respiratory technologists was valued. The professionals who were interviewed recommended there be more time for discharge teaching and planning for families, and believed families needed more information about services available following discharge, the special nutritional needs of their children, the approximate period oxygen was likely to be administered, the developmental needs of children on oxygen and the impact on personal and family life of caring for these children at home. In addition, all suggested improved coordination of services between the hospital and the community. Both the views of the parents and comments from the health professionals in this study reflected recognition that the initial teaching in hospital was only part of the carers’ learning process.

An English research project aimed “to assess the practical, social and emotional impact of HETF [home enteral tube feeding] on the lives of disabled children, their primary carers and the professionals that support them” (Townsley & Robinson, 2000, p. 9). In the first phase of this research, two national postal surveys were conducted to collect information about policies and guidance on home enteral tube feeding. Following this, eight varied locations were selected for in-depth study through semi-structured qualitative interviews with 115 health, education and social care professionals, and parents from 39 families. The interview data showed most parents found deciding to accept HETF was difficult and they were helped by having sufficient
time and information from professionals in order to feel in control of the process (Townsley & Robinson, 2000). Families were also asked about the training they received to manage the tube feeding at home. They reported initial training by hospital ward staff or a relevant nurse specialist, such as a stoma nurse or nutrition nurse, and some had follow-up training at home. “Training was offered on a one-to-one basis and tended to be loosely based on the following structure: professionals and parents discussed the procedures of tube feeding; parents observed the procedures; parents take over the role of administering HETF for their child, initially supervised and monitored by professionals; parents take full responsibility for HETF and child is discharged from hospital. In the main, training was unstructured, ward based, child specific and quick” (Townsley & Robinson, 2000, p. 29). The nature and quantity of training were variable and 11 families felt it was insufficient to successfully manage at home, citing information or training they had lacked, such as how to manage a stoma infection, how to change or re-insert tubes and how to check the placement of a nasogastric tube. Four families claimed they had had no training about HETF before their child was discharged; in two of these instances there were parents trained as nurses, who felt it had been assumed they would know what to do.

Another study about home enteral nutrition took a quantitative approach to investigating the training carers had received (Silver, Wellman, Galindo-Ciocon, & Johnson, 2004). Thirty new carers of older adults receiving home enteral tube feeding were interviewed one to three months after the patients’ discharge from hospital. The structured interview included a Home Enteral Nutrition Caregiver Tasks checklist, three scales measuring caregiver overload, preparedness and competence, and questions regarding the caregivers’ self-perceived effectiveness and health care use by or for the patient. Most carers (21) said they had received training from nurses, three from physicians, two from dietitians, two from medical equipment company drivers who delivered enteral supplies and two had not had any training. Half received training in hospital before discharge, nine at home and four in an outpatient clinic. The Caregiver Tasks checklist contained 33 items in four groups: six functional tasks (such as shopping and personal hygiene), seven care management tasks (arranging appointments and services), 14 technical tasks related to the enteral feeding and six nutrition-related tasks (for example, monitoring weight and hydration). Carers were asked whether or not they performed each task. The mean number of tasks that carers performed daily was 3.73 functional tasks, 5.5 care management tasks, 7.63 technical tasks and 2.87
nutrition-related tasks. In addition, for each task, carers were asked if they had been taught it or not, and whether or not they needed any teaching. On the whole, the number of tasks for which carers reported receiving training (6.3±6.04) was less than the number they reported needing training for (17.9±5.4). Although few had received training for functional tasks, most did not think they needed training in this area (except for lifting/positioning), while almost everyone wanted training for the nutrition-related tasks, yet almost all reported they were untrained for these. Only about half of those reporting they performed any of the technical tasks said they had been trained for them and many said they needed training in this area. The mean caregiver preparedness score was low (1.72; maximum = 4) and positively correlated with caregiver competence (P<0.001) and self-rated caregiver effectiveness (P=0.004) and negatively correlated (P=0.03) with health care use (measured by frequency of phoning or visiting a health care professional for help with the feeding tube, other than at times of planned follow-up). The authors of this study concluded that carers of older adults on home enteral nutrition needed more training to improve both their effectiveness and the nutrition outcomes of those they cared for.

Scott (2001) explored the technological caregiving experiences of family carers of people receiving inotropic infusion therapy (drugs to stimulate the heart, administered intravenously) for end-stage heart failure at home. In this small study, the researcher interviewed four spouse-carers and analysed the interviews using content analysis. Technical care was learnt through formal and informal methods, including observation and imitation of professionals, written material and “trial and error approaches” (Scott, 2001, p. 232). Likewise, problem-solving was learnt both from professional instructions as well as the carers simply trying things themselves.

In another small study, carried out in New Zealand, five adults with a gastrostomy and two of their carers were interviewed about administering medicines via the stoma (Welman, 2007). Four had received limited instruction about administering medications via the tube and had worked out their own techniques (which did not always reflect best practice). The exception was the one participant who lived alone, who had received more training in order to ensure she would be able to cope at home. Interestingly, this same participant was receiving daily district nurse visits while the others, who all lived with family members, felt the district nurses “kept their distance” and they were left to rely on their family for assistance (Welman, 2007, p. 25).
A recent study employed focus groups with 15 parents who were managing an implanted central venous access device and administering clotting factor to their children with haemophilia (Furmedge, Lima, Monagle, Barnes, & Newall, 2013). These parents found a supportive learning environment was more important than a particular teaching process and different learning styles meant a variety of teaching materials and methods were needed. The parents also described their initial anxiety with having to do a painful and risky procedure on their child. Most gained confidence quickly as they discovered the procedure was not difficult, but some concern remained around the potential to harm their child by inadvertently causing an infection. Factors which aided in developing confidence were the aforementioned supportive learning environment, establishing a routine for doing the procedure and having a sense of empowerment and control in being able to manage the child’s care.

There were several recurrent themes in the literature concerning the process of carers learning to manage technical health procedures. The first was their emotional response to the experience. Initial anxiety was common when learning new tasks and when carers first took full responsibility at home, away from familiar back-up assistance in the hospital setting (Henry, 2008; Kirk & Glendinning, 2002; Levine, 1999b; Mentro & Steward, 2002; Ramritu & Window, 1999). While anxiety reduced over time as carers became more confident about performing technical care, they could also face new and perhaps unexpected situations at home (Wennick & Hallstrom, 2007).

In addition to anxiety about mastering a new skill, carers could be concerned about the possibility of hurting or harming their loved one, as noted already in the study by Furmedge et al. For example, Scott (2001) described a carer who was administering an intravenous medication infusion to her husband with end-stage heart failure. The carer reported her anxiety led to her developing hives the first few times she carried out the procedure, due to the stress of “not knowing if I was going to hurt him” (p230). Jerrett (1994) described the distress of a mother of a child with juvenile arthritis who was expected to do regular therapy that caused pain to her child, contradicting a natural parental instinct to try and shield one’s child from pain. She described managing the daily therapy as a “nightmare” (Jerrett, 1994, p. 1053). At the extreme, Brett described the “terror” of a parent going to bed fearing she might wake up to find machines had malfunctioned and her child had died while in her care (Brett, 2002, p. 833).
Concern about causing pain or harm also highlights the emotional involvement of family carers with the person they care for which differs from a more clinical relationship between a professional and their patient or client. Levine (1999b), writing from her experience of eight years caring for her husband with quadriplegia, said: “Caregivers want education and training that recognizes their emotional attachment to the patient. Professionals seldom appreciate how much fear and anxiety complicate the learning of new tasks. Learning how to operate a feeding tube or change a dressing or inject a medication is hard enough for a layperson; caregivers learn how to perform these procedures for the first time on a person they love. Fearful of making a mistake or simply upset by the idea of having to perform unaccustomed and unpleasant tasks, caregivers may resist or fail, or persist at great emotional cost” (Levine, 1999b, p. 1589).

Caring for a family member may also cross normal barriers of intimacy and cause embarrassment or stress for one or both parties (Hale, Barrett, & Gauld, 2010; Surpin & Hanley, 2004).

Another theme in the literature was reference to ‘trial and error’ learning by carers. For example, Brereton and Nolan’s (2002) study of 14 new carers of stroke survivors commented they frequently had to learn the skills they needed by trial and error after discharge, despite trying to seek information and training from staff earlier. However, trial and error learning need not all be negative. Thorne and her colleagues interviewed 46 parents caring for a child with a gastrostomy and described the problem-solving skills and innovation of these parents as they adapted their management of procedures to their home and social environment (Thorne, Radford, & Armstrong, 1997). Successful innovation by these parents increased the carers’ confidence in their own knowledge and skills (Thorne et al., 1997). Nevertheless, as the term suggests, trial and error have the potential to cause harm and lay experience may conflict with professional advice (Spalding & McKeever, 1998; Welman, 2007). On the other hand, rather than increasing risks, carers may also take steps to reduce them. For example, Ramritu and Window (1999) reported that mothers who had been taught a clean (as opposed to sterile) urinary catheterisation procedure had modified it so it was ‘cleaner’ in an attempt to reduce the perceived risk of infection to their children.

Trial and error learning also suggests that learning continues beyond initial training. In the ongoing learning process, carers’ own experiences along with those of other families managing similar care could be as important as education from health professionals (Kime, 2014; Lindahl & Lindblad, 2011). Literature about carers’
learning has also identified that while they want to learn clinical skills and knowledge, they have broader needs too, such as how to communicate effectively with health professionals, information about available legal and financial support, and emotional support both for themselves and the person they care for (Creasy, Lutz, Young, Ford, & Martz, 2013; Silva, Teixeira, Teixeira, & Freitas, 2013).

A third point of note in the literature was references to the development of expertise by carers. Kirk and Glendinning commented on the importance of the experiential and intuitive knowledge that parents of technology-dependent children gained through their caring at home, in addition to formal training in hospital before discharge (Kirk & Glendinning, 2002). Indeed, they refer to this group of carers as “expert parents” (p. 628) and noted their expertise could in time exceed that of professionals. However, carers’ expertise may be a double-edged sword: a UK study involving 22 carers of people with physical and complex disabilities discharged to a home setting after hospitalisation found they valued being taught practical knowledge and several had received training in aspects of care provision, but a few said they had not been offered any training (Heaton, Arksey, & Sloper, 1999). Some believed this was because staff knew they had experience caring and therefore assumed they did not need further training (Heaton et al., 1999). A particular group of carers who may be disadvantaged in this way is professionals such as nurses who may be assumed to have knowledge and experience (Townsley & Robinson, 2000). Koshti-Richman (2009), reflecting on her experience as a nurse and a parent of a disabled child, wrote, “I feel the support I receive for managing his medical needs at home is piecemeal. I cannot help wondering whether this is because I am a nurse and it is assumed that I can cope, or whether this is typical for all parents in situations such as mine” (p. 19).

Various things which can help or hinder carers’ learning have been identified in the literature. On the positive side, Brereton and Nolan (2002) affirmed the importance of a trusting relationship between professionals and carers: “Carers reported an increase in their confidence when they were taught skills by a professional in whom they felt confident themselves. As such there seems to be a reciprocal element to developing confidence - carers need to have confidence in the professional teaching them the skills as well as feeling that staff have confidence in them” (p. 28). In addition, this same study reported that carers needed to have adequate knowledge about their role in order to feel confident that they could care effectively, and they needed feedback affirming their abilities from both staff and the person they cared for. “Unfortunately most carers
reported that few opportunities existed for them to work with staff and to receive feedback about their skills and competence. Consequently, carers did not feel well prepared for caring following the stroke survivor's discharge home” (Brereton & Nolan, 2002, p. 28).

Early information about a new procedure (including pre-operatively where applicable) is helpful for carers (Cooper, 2008). While understanding the clinical indications for a procedure and how it will be managed are important, carers also want broader information (Heaton et al., 1999). For example, parents of children with gastrostomies needed to learn about the care and management of tube feeding but also wondered how to fit this into the everyday life of both the child and family (for example, could the child go swimming?) and how to help the child adjust to a new body image (Craig, Scambler, & Spitz, 2003). New carers have reported appreciating contact with experienced carers for support and advice (Aday & Wegener, 1988; S. Court, McCowen, Hackett, & Parkin, 1989; Craig et al., 2003; Spalding & McKeever, 1998).

Transitions, such as discharge from hospital to home, starting school or changing services can be stressful for families; increased care coordination, advocacy and cultural support at these times can be helpful (Henry, 2008). Having a gradual discharge (for example, an overnight then a weekend stay at home) can enable carers to have a better sense of what they are going to be expected to do and how they will cope at home (Heaton et al., 1999).

In addition to the positives, carers have described a number of problems or difficulties with training. Absent or insufficient preparation have already been mentioned. Training often takes place during a time of stress which impacts carers’ ability to absorb new material (Darbyshire et al., 1997; Mentro & Steward, 2002). In families with children with complex medical needs, training was often focused on one individual, but parents wanted all family members involved to be trained to care (Diehl, Moffitt, & Wade, 1991). A survey of American caregivers (n=1002) found those who worked fulltime were less likely to receive training, perhaps because the timing of instruction was not convenient for them and no alternative was offered (Gould, 2004). Multiple teachers can be problematic if their teaching is uncoordinated (Kirk, 1998) and there is a risk of miscommunication if oral teaching and written materials are not provided in the learner’s own language (S. Evans, Preston, Daly, Neville, & MacDonald, 2011; Povlsen, Olsen, & Ladelund, 2005; Townsley & Robinson, 2000). After discharge, some carers have found there is a lack of support and follow-up in the
community, and a need for more information about what to do when problems arise (Aday & Wegener, 1988; Cooper, 2008).

**Section summary**

There has been little research to date specifically about the experiences of carers managing a technical health procedure at home or their process of learning. In the broader context, caring is not a fixed state but a process of changing roles and adapting to new circumstances. Caring may be stressful, particularly if support or services are inadequate. Carers may feel they have little choice about taking on this role, particularly if alternatives are limited.

Learning to manage technical health procedures for a family member is an emotional as well as practical task which is likely to begin at a time of stress and may involve anxiety about hurting one’s family member. In post hoc studies of training, carers have often commented on being incompletely prepared for the realities of managing at home alone. However, their own further experiential learning may in time result in them becoming expert at managing a procedure. In the next section, we will consider what health professionals have written about teaching technical health procedures, which presents a rather more systematic and extensive process.

**Teaching carers to manage technical health procedures – from the health professionals’ perspective**

In contrast to the limited detail about carers’ experiences and learning of technical health procedures, health professionals have outlined their teaching programmes for particular techniques, such as managing a tracheostomy, gastrostomy, intravenous therapy or urinary catheterisation. This material covers teaching and learning personnel, the teaching location, content and methods of teaching, the transition to home care and ongoing learning and support in the community, and evaluation of training. The literature reviewed in this section is based on a range of studies, representing mixed and multiple methodologies: empirical studies, practice guidelines, local teaching programmes, and commentaries. The type of work is not always made explicit, which is in part why formal critical appraisal of this section of
the literature review was deemed to be inappropriate. In turn, the nature and range of this literature supports the narrative review approach taken throughout this thesis.

**Initial considerations for teachers**

Teaching and learning have been presented as a process, with recommendations to start with basic skills before moving on to the more complex once mastery and confidence increase (Bilodeau, 1995; Fiske, 2004; Foster, 1993; Kennedy, Johnson, & Sturdevant, 1982). Although many articles have provided lists of information and procedural steps that need to be taught, there is recognition that generic curricula need to be individualised according to readiness and ability to learn, learning styles, ethnic and language needs and at the individual’s own pace (American Thoracic Society, 2000; Bilodeau, 1995; J. M. Court, 1989; Kennedy et al., 1982; Kennelly, 1987). Marcuz (1980) also highlighted the importance of a trusting relationship developing between educator and learner if effective teaching was to occur.

Learner suitability is another important consideration for health professionals. For example, Mighten (2007) provided some specific criteria for identifying families that could manage home intravenous therapy for children. These included aspects of the home environment (enough space for therapy, cleanliness, access to a telephone, no younger siblings) as well as parents’ literacy and numeracy skills and their manual dexterity. The care recipient could also have a role in determining who is involved in their care - writing about relationships between parents and nurses caring for children in hospital, Darbyshire (1994) noted, “Parent participation seemed to be shaped and determined by a dynamic process involving both parents and nurses…The influence of the child should not be overlooked, however, as their insistence that the parent was to stay with them and help with any particular care task also had an influence upon a parent’s decision to participate” (p. 108).

Timing of training can influence readiness for learning. For instance, parents whose child has been diagnosed with diabetes may initially be in shock, anxious and forgetful of new information, so learning is likely to be difficult or overwhelming at this time (J. M. Court, 1989; Foster, 1993). In other situations, a new care need may be anticipated in advance and some preliminary teaching can begin beforehand. For example, introductory information about tracheostomies and their care can be given before elective surgery (American Thoracic Society, 2000; Fiske, 2004; Kennedy et al.,
1982). Rathlev and McNamara (1982) suggested preparation should also include information about available support, including from other experienced carers.

**Teachers and learners**

Who teaches carers to do procedures such as nasogastric feeding or changing a tracheostomy tube and whom do they teach? The teaching professional is not always explicit in the literature, but is probably reflected by the discipline of journal article writers; for example, a nurse writing about teaching urinary catheterisation (Martins, Soler, Batigalia, & Moore, 2009), nurses and dietitians discussing enteral nutrition (S. Evans et al., 2010; Sexton & Holden, 2000) and physiotherapists investigating physiotherapy education for parents of children with cystic fibrosis (Tipping, Scholes, & Cox, 2010). A multidisciplinary approach may be needed, particularly to support people with complex needs and their carers (Fiske, 2004; Ruben et al., 1982). Inconsistency of teaching may be a problem when there are multiple teachers (Mighten, 2007).

The person to be trained is often referred to in the literature simply as a family member or in the case of children, the parent/s. For tracheostomy care, it has been recommended that at least two family members are trained, or one primary carer and a backup, because of the need for continuous supervision (American Thoracic Society, 2000; Kennedy et al., 1982; Ruben et al., 1982). In other situations, training multiple carers is also regarded as beneficial as they can support one another and share the responsibility for caring (Bilodeau, 1995; J. M. Court, 1989).

Most literature seems to assume individual or perhaps family teaching, but there are some examples of group teaching. Cobussen-Boekhorst et al. (2010) wrote about group teaching for children who had not succeeded in learning to perform clean intermittent self-catheterisation through their usual individual teaching programme. The children’s parents were included in the further training, sometimes with their children and sometimes apart, with opportunity to share their own experiences and difficulties. All the children in this programme succeeded in learning to manage their own self-catheterisation and the mutual support appeared to have been valuable for both the children and parents, with some continuing contact after the programme ended. Mutual support was also reported to be a positive feature of a family day camp for children with diabetes and their families (Koukal & Parham, 1978).
While such ‘support’ between carers may be lauded, health professionals generally appear to assume they should retain control of teaching. For instance, a study of 34 children receiving home enteral tube feeding found 71% of their secondary family carers had not been instructed by a health professional; rather, the child’s mother (the primary carer in all cases) had taught them (S. Evans, MacDonald, Daly, Hopkins, & Holden, 2007). Later in the article, these secondary carers were described as being “untrained” (p. 443) and concern was expressed about the safety of their caring, although this had not been assessed.

**Teaching location**

Varied teaching locations are apparent in the literature. An inpatient setting seems to be commonly assumed and may be both practical and necessary (for example, when learning to care for a ventilator-dependant patient). However, some procedures may be taught initially in an outpatient or home setting (Berezin, Medow, Bernarducci, & Newman, 1988; Martins et al., 2009).

A few studies have compared teaching settings, such as an American study which compared the efficacy of outpatient and inpatient programmes on medical, cognitive, behavioural and psychosocial outcomes for children newly-diagnosed with diabetes (Siminerio, Charron-Prochownik, Banion, & Schreiner, 1999). Sixteen children and their parents receiving training through an inpatient programme at one hospital were compared with 16 children and parents taught in outpatient programmes at two other hospitals. The first hospital routinely taught children as inpatients while the other two routinely provided outpatient teaching unless the child was very ill (70% of children at one institution were taught as outpatients and 40% at the other). All three sites had a standard curriculum and their teaching tools and methods were similar. Parents completed a number of questionnaires at the end of the education programme and one month later and from these, seven outcome variables were compared between the groups: rates of hospital readmissions and/or emergency room visits for either severe hypoglycaemia or ketoacidosis; knowledge; sharing of responsibilities; adherence; family functioning; coping; and quality of life. The reported results showed no significant differences between the groups and the authors therefore concluded an outpatient teaching programme for diabetes was safe and efficacious. However, they
also noted this was not a randomised or controlled trial and recommended such a study be undertaken with longer follow-up as well as cost comparisons.

Another American study compared patients and carers taught nocturnal nasogastric feeding techniques either as hospital inpatients or at home (Berezin et al., 1988). Eighteen families were alternately assigned to each group. Those taught at home were able to perform the procedure after one teaching session which averaged 3.2 hours, whereas the mean hospital stay for learning was 3.4 days. No-one in either group experienced associated complications. The authors concluded this procedure could be safely taught at home at less cost than hospital teaching. They noted home teaching would also avoid a potentially unpleasant hospital experience and the risk of nosocomial infection.

Sawyer and Glazner evaluated a five-day residential programme for the parents of infants with newly-diagnosed cystic fibrosis (CF) in Melbourne (n=15 families; 15 mothers and 12 fathers) (Sawyer & Glazner, 2004). The setting was a Care-By-Parent unit at a regional hospital where both parents were encouraged to stay for initial cystic fibrosis education and meetings with relevant professionals. Parents evaluated the programme positively (through a structured phone questionnaire) and the investigators considered “the key elements that contribute to the success of this program are prompt timing immediately after diagnosis, engagement of both parents, clear and comprehensive communication at all stages, the opportunity for supervised skill development (eg, pancreatic enzyme administration, chest physiotherapy), and the expertise of the CF team. An additional factor that is recognized to be valuable for parent education generally is the provision of written material” (Sawyer & Glazner, 2004, p. 414). However, the authors also recognised there was no comparison setting for this programme and suggested other training options could be inpatient admission or a non-residential day programme; the home setting was not mentioned, perhaps because it would be time consuming and less convenient for the multiple professionals involved to make home visits. The evaluation concluded, “It seems likely that the setting (residential vs nonresidential) and the exact duration are less relevant than the context and content of the program, particularly how well the program supports parents through this difficult time and how well it assists parents to engage with their child’s ongoing health care” (Sawyer & Glazner, 2004, p. 415).
**Teaching content, methods and duration**

Some plans for teaching programmes have been provided in the literature. For example, Rathlev and McNamara (1982) outlined the content of their eight sessions for teaching families tracheostomy care, while another tracheostomy and ventilator care curriculum was set out in 12 sessions (J. M. Dougherty, Parrish, & Hock-Long, 1995). Rather than define specific sessions, others have simply listed the material that should be covered (Bilodeau, 1995; J. M. Court, 1989; Hotaling et al., 1995), perhaps in recognition of the need for individualisation and that different people will take varying amounts of time to learn the same skills.

The teaching topics outlined in a recent clinical consensus statement on tracheostomy care (Mitchell et al., 2013) were entirely focused on the clinical knowledge and skills that needed to be taught, with no consideration of social or psychological needs of either the carer or recipient. On the other hand, an article addressed to nurses teaching parents to manage their child’s tracheostomy care stated, “The primary goal of teaching is to help parents adapt to the home care of their infant with a tracheostomy” (Joseph, 2011, p. 233) and highlighted the importance of psychological and social support in achieving this. Only then was the secondary goal added, namely “to help the parents develop the skills necessary to care for the infant with a tracheostomy independently at home” (Joseph, 2011, p. 233); this also included identifying community support for both the child and parents. A New Zealand study utilised focus groups with 17 community palliative care health professionals to elicit their thoughts about what carers needed in order to be equipped for their role (Angelo, Egan, & Reid, 2013). In addition to practical skills, the participants identified two other important aspects for their education: knowing what would happen as the patient’s condition deteriorated and the need for carers to look after themselves too (Angelo et al., 2013).

In addition to teaching practical skills, some health professionals have emphasised the importance of helping carers develop decision-making skills (e.g. Barnes, 1992; Kennelly, 1987). Kaufman and Hardy-Ribakow (1988), writing about teaching tracheostomy care, observed that, “Oddly enough, families frequently find that mastering these complicated procedures is actually the easy part. Deciding when to perform them is much harder, because of fear and emotional involvement” (p. 100).
Training has been described as a stepwise process (Bathie & Shaw, 2013) with an orderly progression of the learner from “a detached observer to an involved performer, a confident problem solver, caretaker, and a resource person for other parents” (Joseph, 2011, p. 233). A paper about training parents to care for their child with type 1 diabetes (Niedel, Traynor, Tamborlane, Acerini, & McKee, 2013) presented this as a process of developing parents’ expertise. Analysis of outpatient interactions between health professionals and parents in the first year following the child’s diagnosis showed the professionals used four strategies to achieve this: “Clinicians begin by setting expectations to define the shared responsibilities for the management of the child’s disease. Next, they introduce two concepts, trial and error, to help parents respond to variations in blood glucose values and pattern recognition, to help parents refine therapy. As parents gain confidence, clinicians encourage independent pro-active management” (Niedel et al., 2013, p. 70).

A feature of literature by health professionals is advice to assess learning needs and plan and document teaching programmes in order to provide a framework for orderly and consistent teaching (Hooker & Kohler, 1999; Kelo, Martikainen, & Eriksson, 2013; Kennedy et al., 1982; Vidler, 1999). Where multiple teachers are involved, having a written plan helps to coordinate teaching and record what has been done (Hotaling et al., 1995). In addition, documentation verifies that teaching has been completed and the carer’s competency has been assessed and demonstrated (Bilodeau, 1995; Hooker & Kohler, 1999; Khair, 2003; Mighten, 2007; Rathlev & McNamara, 1982; Vidler, 1999).

Some professionals have used contracts with carers to define responsibilities and training expectations (Kirk, 2001; Wong, 1999). McCarthy (1986) gave an example of the type of contract used at the time by The Children’s Memorial Hospital of Chicago in preparation for home discharge of ventilator-assisted children. In this sample, the parents made eight undertakings, including attending classes and meetings with a variety of professionals, being available for care one eight-hour period during the week and assuming total care for one eight-hour shift alternate weekends. The contract was for an initial eight weeks and was to be signed by both parents, the primary nurse, physician, respiratory therapist and social worker. According to McCarthy, “This contract commits the staff to teaching the parents all aspects of the child’s care. Parents agree to learn this care and demonstrate their competence by independently caring for the child during a set number of shifts over a given
period…Once the contract terms are fulfilled, an objective decision can be made regarding home discharge” (p333).

The literature presents a range of teaching methods. A common approach seems to be allowing carers to observe while professionals demonstrate and explain a technique, then assisting the carer to practice with supervision and feedback on their performance (Hendrix, Abernethy, Sloane, Misuraca, & Moore, 2009; Kennedy et al., 1982; Kennelly, 1987; Parmar et al., 1993). Carers may do their own learning from observation alone – in discussing home visits by professionals in an American early intervention programme, Leiter (2004) noted that mothers appreciated watching professionals work with their children and learnt through observing and asking about what was being done.

Rather than learning directly on a patient, dolls or mannequins may be used initially. Posited advantages of this method include: the learner is not stressed about causing distress to the patient; anxiety, fear and embarrassment about performing the procedure are reduced; errors can be made and corrected without harm; there may be more opportunities for practice; and confidence increases (Cobussen-Boekhorst, Van der Weide, Feitz, & De Gier, 2000; Neef, Parrish, Hannigan, Page, & Iwata, 1989; Sexton & Holden, 2000). Another situation where indirect learning may be required is for potential problems or emergencies that cannot readily be observed or practised. Role playing has been suggested in these situations (Kennelly, 1987; Ruben et al., 1982).

A small pilot study added one session of 60-90 minutes practice with a simulator to their training programme for parents learning to manage their child’s home ventilator (Tofil et al., 2013). Seven of the 15 parents completed a phone survey three to six months after finishing their training. All agreed the simulator training was helpful and gave them confidence in preparing to care at home and they would recommend it to other parents. They identified several advantages: “(a) the ability for hands-on learning, (b) the ability to practice [sic] rare emergency scenarios, and (c) the realness of simulation” (Tofil et al., 2013, p. 1039). However, in addition to the small sample and low response rate, there was no control group or comparison with a previous training group.

Written resources may be provided as an adjunct to teaching, to reinforce what has been taught and for later reference when required (Hooker & Kohler, 1999; Lee & Headland, 2003; Noble, 1992). A Cochrane review of written and verbal information
versus a control of verbal information only for patients when leaving acute hospital settings found just two relevant trials (Johnson, Sandford, & Tyndall, 2003). Both involved information being provided to parents of children as they were discharged from hospital, in one case, following treatment for burns in an American hospital and in the other, for otitis media at a Canadian hospital. In both studies, there was a significant increase in knowledge in the groups receiving written in addition to verbal information, compared with verbal information only, and the review recommended providing both written and verbal discharge material. However, their conclusions were limited by the small number of studies included, and most of the review questions were unable to be answered because of insufficient data.

Examples of written material in the literature ranged from a double-sided information and instruction sheet given at discharge to patients and families with a percutaneous endoscopic gastrostomy (Noble, 1992) to a nine page guide for parents doing home tracheostomy care for their child (Lichtenstein, 1986). Such guides include checklists, bulleted or numbered steps, diagrams and photos, and advice about potential problems and their management. Some provide space for patient-specific information and contact details for professional support (Burd & Burd, 2003a).

Health professionals and institutions may not have the resources to produce their own materials but a plethora is already available, as illustrated by a US directory of patient education resources on home nutrition support. The 1993 guide listed 33 items; in 1995 there were 41 and by 2010, about 150 (M. A. Evans, 1993; M. A. Evans & Czopec, 1995; Metzger, 2010). Most of these were written resources, but in the latest directory, about 10% were DVDs or online videos. Content and reading levels varied.

Some authors have discussed the development of their written resources. A manual for parents caring for a child with a tracheostomy was produced by a nurse clinician following a review of literature and other relevant manuals and pamphlets (Kingston, Brodsky, Volk, & Stanievich, 1995). The content of this manual was critiqued by two senior paediatric otolaryngologists and in order to present the material well and with an appropriate reading level for its audience, a reading expert, commercial artist and medical photographer gave assistance. The manual was then piloted with 21 families of children with long-term tracheostomies already at home, who had not had the benefit of such material. They were asked to complete a questionnaire to evaluate how easy they found the material to understand and how useful it was. Over 90% of all the written content was rated useful and easy to
understand and similarly all bar one illustration. Suggestions for additional information and photos were to be incorporated into future revisions.

Martins developed a culturally-specific, Portuguese-language booklet for teaching clean intermittent catheterisation to carers in Brazil (Martins et al., 2009). However, in addition to professional input during development, she also sought advice from experienced carers. Language was pitched at the average literacy level and illustrations were used to demonstrate all the steps in the procedure. The booklet was designed to be used alongside individual teaching, to reinforce the nurse’s verbal information and demonstration of the technique. The booklet was trialled with 23 carers who were beginning to learn clean intermittent catheterisation and their suggestions were incorporated into a revised version. “During the teaching sessions, many caregivers said that the booklet gave them security and was a ‘comfort,’ particularly initially, when they could check their technique as well as share the information with others” (Martins et al., 2009, p. 549).

Lehoux, Saint-Arnaud and Richard (2004) explored the use of technology at home (intravenous antibiotic therapy, parenteral nutrition, peritoneal dialysis and oxygen therapy) through interviews with patients and carers, observation of nurses’ home visits and analysis of the content and structure of 26 patient manuals from product manufacturers and hospitals. They found the manuals produced by manufacturers were “…more concise (pocket format), relied more extensively on graphic representations to explain a step-wise approach to using the device, and focused on technical characteristics (alarms, maintenance, power sources). In contrast, those produced by hospitals addressed clinical and psychosocial topics such as the disease itself (onset, symptoms, evolution, physiological aspects), aseptic procedures, handling the device, emergency procedures and contacts, personal hygiene, diet and physical activity, and impact on family relationships” (Lehoux et al., 2004, p. 628). Both types presented learning as an ordered process and there was an assumption that all learners would have the same cognitive, language and physical abilities. In addition, these written materials gave only positive presentations of the technology; in contrast, users were more ambivalent about their benefits and adapted the standard usage to suit their own situation (Lehoux et al., 2004).

Few articles referred to another possible source of written support for carers, namely websites. However, one guide included references for two websites with parent information (Burd & Burd, 2003a) and in an article for professionals, the same authors
provided a longer list of web-based resources for families (Burd & Burd, 2003b). A further way to provide or reinforce information for carers may be videos or DVDs which may be particularly useful for learners with poor literacy or carers unable to attend education in person (Foster, 1993; Hooker & Kohler, 1999).

Most literature about teaching methods was descriptive. Foster (1993) applied Bandura’s social learning theory in developing a teaching plan for parents caring for a child with a stoma. Utilising this theory’s emphasis on observation and practical experience in learning, Foster recommended nurses demonstrated techniques then allowed patients to practise them with support. Conversely she advised against verbal instruction without hands-on practice (Foster, 1993).

There was little information in the literature about the time needed to teach particular procedures. The length of a teaching session may need to be tailored to availability of both staff and learners and to concentration spans; one paper suggested sessions of about 45 minutes (Rathlev & McNamara, 1982). The American Thoracic Society statement on care of children with tracheostomies did not quantify the total time required for training, instead linking the necessary duration to individuals’ demonstrated competence (American Thoracic Society, 2000). Yet while carers need time to understand new information and become proficient with new skills at their own pace, professionals have also recognised that short hospital stays and pressure to discharge patients can make this ideal difficult in practice (Mezey, 2004; Wong, 1999).

**Transition from hospital to home care**

Carers who have undertaken a training programme in a hospital setting must transition to caring at home and on their own. To facilitate this, the new learner may be given the opportunity to manage all aspects of care on their own but within the hospital environment where back-up is available (Bilodeau, 1995). Another intermediate step that has been suggested is an overnight stay at home before discharge (Heaton et al., 1999; Ruben et al., 1982). Staged responsibility like this may help the transition from hospital to home, affirm carers’ confidence in their abilities and allow staff to monitor and evaluate whether a family is ready for discharge (American Thoracic Society, 2000; Fiske, 2004; Kennedy et al., 1982; Wong, 1999). Bilodeau (1995) suggested nurses create a non-harmful equipment malfunction during this phase to test the carer’s knowledge in dealing with contingencies.
Having the ability and confidence to manage a procedure within the hospital environment during supervised training may differ from the experience of doing this alone at home, as suggested by a pilot study of an in-hospital training programme for 20 carers of patients with haematological malignancies (Hendrix et al., 2009). A carer self-efficacy measure was used before and after training and one week after discharge. The results showed self-efficacy had increased at both times after training compared to beforehand, but there was some decrease after discharge. From this, the authors deduced that ongoing nursing support and training were needed post-discharge (Hendrix et al., 2009).

Differences between hospital and home caring need to be considered in the training process (for instance, ‘clean’ suctioning of a tracheostomy at home versus a sterile technique in hospital where infection risks are higher (Ruben et al., 1982)). Leaving the security of hospital can be a stressful time for carers, and changes in equipment or processes between the hospital and home settings can create anxiety (Bakewell Sachs & Porth, 1995; Cameron & Gignac, 2008). Carers therefore need to learn and practise on the same equipment in hospital that they will use at home (American Thoracic Society, 2000; Wong, 1999), yet this may be problematic if hospital equipment differs from what is provided in the community, and hospitals may preclude non-standard apparatus from being used there (Khair, 2003).

**Learning and support at home after discharge from hospital**

Professional teaching and support may continue after discharge. In some cases, a professional may be with and assist a family on their initial day at home (Bilodeau, 1995). There may be pro-active phone calls from hospital staff to see how carers are managing at home and/or carers may be given contact details to phone for help if required (Bilodeau, 1995; Mighten, 2007; Ruben et al., 1982).

Home visits can provide an occasion for staff to monitor whether techniques are being followed as taught (Ruben et al., 1982; Vidler, 1999) and give an opportunity for carers to ask questions and get advice about new situations that have arisen (J. M. Court, 1989; Vidler, 1999). Thus carers’ learning continues beyond the initial intensive training period and some health professionals have suggested carers may be encouraged to extend their technical skills at home. For instance, carers who were initially reluctant to replace a nasogastric tube or a tracheostomy tube in hospital may be supported by
community staff to learn to do this themselves (Khair, 2003; Ruben et al., 1982). There appears to be an expectation by professionals that carers will continue to progress to full independence and professional support will decrease as this is achieved (Bilodeau, 1995).

**Evaluating training or learning**

A few studies have considered the effectiveness of various teaching methods or evaluated training or learning. Kalra et al. (2004) reported on a randomised, controlled trial comparing a training programme with conventional support for carers of people who had had a stroke (n=300). A variety of factors were measured three months and a year after the stroke. The trained carers showed significantly less burden, anxiety and depression at the one year assessment than the control group (Kalra et al., 2004). However, while the training included information about strokes and care activities, there was no specific mention of technical health care, so this study suggests a general benefit from carer training rather than addressing the focus of this thesis.

Geiger, Heermann and Eilers (2005) noted that “Despite the significant amount of time that nurses spend teaching patients and family members, its effect is often not known” (p. 55). They described their process (using a focus group of health professionals) to identify and validate competencies for use in objective structured clinical examinations (OSCEs) for lay carers preparing to care for a blood and/or marrow stem cell transplant recipient. The next phase of this study was to be pilot-testing of the OSCEs with carers (Geiger et al., 2005) but results of this have not been reported. However, an earlier study using modified OSCEs to verify technical skill performance and competency of 13 lay carers concluded this was feasible and accurate (Heermann, Eilers, & Carney, 2001). While OSCEs can be used for a pass/fail assessment, the purpose here was to appraise carers’ knowledge and clinical skills in a non-threatening way. Carers were given immediate feedback during the OSCE assessment as a way of enhancing confidence and reinforcing learning. Pre- and post-test data on the participants’ self-assessment of the three procedures tested showed a 50% improvement in their level of comfort with their skills, 65% improvement in self-perceived ability and a 75% reduction in information needs after compared with before the OSCE (Heermann et al., 2001).
Developing and implementing OSCEs could be quite time and resource consuming. Other studies have used written tests of carers’ knowledge before and after training. Fathima (2004) assessed the usefulness of an information booklet she developed for carers of patients having haemodialysis. She used a structured questionnaire to test the knowledge of a convenience sample of 30 carers before and one week after giving them the booklet, concluding there was a highly significant improvement in carers’ knowledge. However, there is no information about how the booklet was used (whether it was simply given to people to read, or if a professional also went through the material with them) and no longer-term evaluation of the retention or application of the knowledge. Other studies that have reported the use of pre- and post-tests to evaluate carers’ knowledge include Tearl & Hertzog’s (2007) evaluation of an education programme for families with technology-dependent children, which showed a statistically significant improvement in carers’ knowledge immediately after training, and K. Brown and Sauve’s (1994) evaluation of an education programme for carers of children on home oxygen therapy, which reported significantly higher post-test scores (both immediately after training and six weeks after discharge) compared with pre-test scores. Both assessed small numbers of carers (20 and 18 respectively).

Any assessment of carers has the potential to be stressful for them so feedback is more likely to be effective when there is a good relationship between carers and their teachers (Tipping et al., 2010). Assessment soon after training may not indicate how well knowledge is retained or whether training is put into practice in the home setting. In an English study, a dietitian and nurse visited families doing home enteral tube feeding (HETF) with children to observe their practices and gather information with a questionnaire (S. Evans et al., 2011; S. Evans et al., 2010). HETF requires the preparation of complex formulae, managing nasogastric tubes or gastrostomies and equipment such as pumps. Errors have the potential to cause serious harm. Forty families had been trained in the hospital setting before discharge – 55% said they had five or more days of training; 18% one to four days and 28% less than six hours (S. Evans et al., 2010). In the home setting, the researchers observed high rates of poor hygiene, inaccurate ingredient measuring, poor management of tubes and patient positioning, untrained secondary carers and poor knowledge about the feeding pumps (S. Evans et al., 2011; S. Evans et al., 2010). They recommended better initial education with regular updates and monitoring, and that ready-to-use ingredients would
be helpful. These studies did not detail what the initial training entailed or how carers were assessed as being ready to manage at home, but the questionnaire and observation checklist were based on the original hospital training criteria. Although carers were presumably judged to be competent before they were sent home, that training may not be remembered or applied as professionals would wish in the home setting.

Evans et al. completed a third year’s follow-up of 32 family carers managing HETF (S. Evans et al., 2012) and found that knowledge had increased in five out of six areas, but as before, many techniques had deteriorated from standard practice. The paper did not report whether any of these apparent deficiencies had resulted in harm, but concluded, “There is a need for annual reassessment of HETF [home enteral tube feeding] skills, including mandatory training updates” (S. Evans et al., 2012, p. 524).

On the other hand, a study in Poland comparing the incidence of catheter-related bloodstream infections in children receiving home parenteral nutrition prepared either in a hospital pharmacy (n=43) or by their parents at home (n=138) found a slightly (though insignificantly) lower infection rate with home preparation, thereby concluding home preparation was safe (Friedman-Gruszczynska, Ossolina, Popinska, & Ksiazek, 2013). Both these papers reflect health professionals’ concerns with patient safety as a driver for carer training.

An American study assessed carers’ knowledge about tracheostomy and home ventilator emergency care for children with chronic respiratory failure (Kun, Davidson-Ward, Hulse, & Keens, 2010). Although parents were trained in emergency procedures before discharge, most had not had to manage an emergency before going home. Primary carers of 83 children on home mechanical ventilation (108 family carers and 44 home nurses) completed a questionnaire testing their emergency care knowledge. Participants scored an average of 81% correct responses (range 48-100%), and there were no significant differences between the lay carers and nurses, between those of differing length of experience (from less than a year to over five years) or between those who had had a recent emergency at home and those who had not. The researchers concluded most carers (both nurses and family members) understood what to do in an emergency and home mechanical ventilation was safe for these children, but specific areas of technical knowledge identified as commonly incorrect would receive more attention in future training.

Another evaluation study has reported on outcomes from training carers to give subcutaneous injections to palliative care patients at home (Healy, Israel, Charles, &
Reymond, 2013). The programme was rated highly by both carers (n=76) and nurses (n=53) who delivered the training, although some nurses expressed concern about the safety and appropriateness of lay carers managing this task. In a second phase of this study, carers were randomised after their training into three groups (Healy et al., 2011). All delivered subcutaneous medication but only one group of carers actually prepared the medication (n=34); in the other groups, the medications were drawn up by a nurse (n=35) or pharmacist (n=37). Data about the carers’ confidence in administering the injections found no significant differences between the three groups, while all groups showed a significant increase in confidence with experience (as measured over a maximum of two weeks after training) (Healy et al., 2011).

In addition to studies reporting professionals’ evaluations of carers’ knowledge and skills acquisition through teaching programmes, a few studies consider carers’ views of their training. Carer assessments of some written materials have already been discussed. Two programmes teaching tracheostomy management surveyed parents who had taken part, although the reported responses were brief: “Eighty percent of respondents felt well-prepared to take their child home from the hospital following tracheotomy. Ninety-three percent agreed that the material presented was helpful and appropriate to the age of their child” [n=30] (Hotaling et al., 1995, p. 123) and “the caregivers expressed a high degree of satisfaction with the program” [n=20] (Tearl & Hertzog, 2007, p. 171). It should also be noted that these were small numbers of carers who would probably continue to interact with their trainers (a single respiratory therapist in the case of the latter study); the need to maintain good relationships with health professionals involved in their child’s care and the possibility that ‘anonymous’ questionnaires could be identifiable mean there might have been strong social pressures to agree that training had been good.

**Section summary**

The literature about teaching technical health procedures which comes from a health professional perspective presents a rather more systematic and comprehensive approach than was apparent in the carers’ experiences. The health professionals’ focus appears to be transferring technical skill and knowledge, with little recognition of the emotional needs of learners or the implications of managing these procedures in the home and family context. Interest in documenting teaching and ensuring learner
competence belie profession concerns about risk and patient safety. This leads us to consider next some of the issues at the interface of professional and lay care.

**Interface issues**

This section examines some of the tensions that arise when technical health procedures, which have traditionally been the domain of health professionals, are transferred to the control of lay carers. These include defining the boundaries between professional and lay roles, issues of professional responsibility and liability, and monitoring of lay carers.

As noted earlier in the introduction, trends such as decreased institutional care, increasing survival of people with complex conditions, technological developments and efforts to contain health care costs have all been contributing to increasing community care. As a consequence, more care has been shifted onto family carers and the boundary between formal and informal care may become blurred, particularly when family carers take on intensive and complex care roles (Kirk & Glendinning, 1998). Guberman et al. (2005), from their analysis of interviews with patients, family carers and health professionals regarding early hospital discharge and home care, argued that the transfer of skilled care from health professionals to family members was accomplished through a process of “trivialization” (p. 247) whereby complex activities were presented as simple tasks which lay carers could undertake. They also asserted the underlying rationale for this shift was financial rather than any evidence of greater health benefits (Guberman et al., 2005).

A related interface exists between health professionals such as nurses and paid but non-professional carers in the community (such as home care assistants). Non-professional staff are restricted in their scope of practice and work under professional oversight, yet family carers are exempt from such constraints (Benjamin, 2001; Surpin & Hanley, 2004). However, there are trends towards shifting the boundaries of professional practice. Here in New Zealand, the government’s blueprint for *Better, Sooner, More Convenient Health Care in the Community* (Ministry of Health, 2011) endorses a team approach in order to do more, which “requires doctors, nurses and other health workers to work together more closely, and in some cases to train others to do certain tasks or procedures” (p. 5). The document then gives examples of general practitioners doing what were previously hospital specialist treatments and nurses
taking on more complex roles, in turn divesting some nursing tasks to others with less
training or no formal health qualifications at all.

Pickard, Jacobs and Kirk (2003), drawing on three studies of lay carers, outlined
three broad health professional views about whether or not carers’ roles should be
restricted:

- “At one extreme, some professionals maintain that there are a range of activities
  which should only be performed by professionals (this includes activities that we
  know from our three studies lay carers are in fact carrying out).

- In the middle position, other professionals claim that carers are capable of being
  trained on a wide variety of tasks, although certain activities should more
  appropriately be performed by professionals.

- At the other extreme, some professionals suggest that carers are trainable in the
  entire range of activities and that in certain activities they are ready to concede that
  they may have a greater expertise than professionals themselves” (Pickard et al.,
  2003, p. 88).

The configuration of health services also influences the roles carers are expected
and allowed to take on. For instance, Ward-Griffin and McKeever (2001) studied the
relationships between community nurses and family carers of older people and
concluded the nurses’ workloads and funding constraints were important factors driving
the transfer of more care to families.

It has already been noted that over time, family carers may become more expert
than professionals vis-à-vis particular tasks or with regard to knowledge of an
individual’s needs (Pickard et al., 2003). This can produce tensions and raise issues of
power in professional-carer relationships. While health professionals control the
hospital setting, the home is the family’s domain and the position of professionals may
that he or she has the professional expertise to render the care correctly and does not
wish to take direction from a nonprofessional family member or even the patient. At
varying times the nurse can be seen as colleague, supervisor, teacher, caregiver,
subordinate, or hired help. This shifting identity can be a barrier to effective caregiving
by each party” (p. 96). Conversely, carers may experience a loss of autonomy if the
person they care for is admitted to hospital. While some may be willing or indeed want
to relinquish responsibility at this time, others may resist being told what to do (Reeves
et al., 2006). Overall, carers may be in the contradictory position of, on the one hand, being responsible for complex tasks, while on the other hand, being expected to defer to and comply with professional advice (Kirk, 1998). The ideal may be a negotiated partnership, though this may not be achieved easily (Henry, 2008; Kirk & Glendinning, 1998).

Issues of professional power are intertwined with concerns about risk and liability. For instance, nurses may be concerned about being held responsible for care given by parents to hospitalised children (Janis Brown & Ritchie, 1990; Power & Franck, 2008). Where professionals are teaching family carers procedural skills, there are references in the literature to their legal responsibilities and duty of care with regard to training (Mighten, 2007; Vidler, 1999). While responsibility for managing a clinical procedure may then transfer to a family carer in the community, professionals may be uncertain about who holds accountability for care in this setting and may engage in ongoing overt or covert monitoring of carers’ competence (Kirk & Glendinning, 2002). Monitoring is also motivated by concerns for the care recipient’s safety (e.g. S. Evans et al., 2010). The World Health Organization’s *Ethical Choices in Long-Term Care* recognises society’s responsibility to monitor quality of care for vulnerable people and to oversee public resources committed to supporting family caring, whilst also noting the tension of what may be seen as state interference in the private realm of the family (World Health Organization, 2002). Carers in turn monitor professionals and their concerns about professional competence can affect relationships and the willingness of carers to relinquish care or accept support (Darbyshire et al., 1997; Findeis, Larson, Gallo, & Shekleton, 1994; Heaton et al., 1999; Kirk, 1998; Thorne et al., 1997).

As this section shows, trends towards increasing community care have both permitted and necessitated increased management of complex procedures by family members. However, new issues around responsibility, risk and safety appear unresolved at this stage.

**The expert carer**

The rising incidence of chronic conditions and their demands on the health system have been paralleled by a growing emphasis on patient self-management and the development of programmes (both professional and lay-led, and either generic or disease-specific) to encourage greater self-management by patients (Battersby, Lawn,
In particular, the UK Department of Health introduced a national patient self-management initiative in 2001 called the Expert Patients Programme or EPP (Department of Health, 2001). Despite its name, the EPP was focused less on a patient perspective than on training them to develop expertise as defined by professionals. Hence the programme has been criticised for creating an idealised patient who self-manages and that rather than empowering patients, it may increase professional control and surveillance of people’s lives and encourage further compliance with the medical model (A. Rogers, 2009; Wilson, 2001).

A corresponding expert carer programme called Caring with Confidence was funded by the UK Department of Health from August 2008 to September 2010 then discontinued because of concerns about its cost and failure to meet targets (Yeandle & Wigfield, 2012). However, carers’ training courses which were developed through this programme are still available through some organisations and online (NHS, 2013a, 2013b). The online workbooks cover “Finding your way” (an overview of the training programme), “Caring and coping” (the emotional aspects of caring and dealing with stress), “Caring and me” (maintaining one’s own health), “Caring day by day” (managing practical tasks such as lifting, medication and emergencies), “Caring and communicating” (with health and social service providers), “Caring and life” (balancing caring with other roles and needs) and finally “Caring and resources” (financial supports) (NHS, 2013b). Notably absent from this broad curriculum is any suggestion that carers may need training for managing technical health procedures. A New Zealand example of online resources for carers can be found at a website developed by Carers New Zealand, although once again, technical health procedures are not included (see http://www.carersair.net.nz/).

Sadler and McKeivitt (2013) have argued that programmes to train ‘expert carers’ have created a new model of the carer, emphasising semi-professionalised, technical skill rather than affective relationships and the development of experiential knowledge. From a Foucauldian viewpoint, they considered this an extension of medical control over the role of carers (Sadler & McKeivitt, 2013).

There are other, scattered usages of the term ‘expert carers’ in the literature which do not refer to training programmes but recognise that carers may become highly skilled through their caring work. Here, the expert carer is presented as someone with detailed knowledge about how to care for their relative and who is able to navigate and be an advocate for their family member in health, education and other social systems.
While the concept of the expert carer has been gaining traction in the literature, there is little detail about the nature of that expertise or how it is developed. Turning to health professional literature, Benner’s (2001/1984, 2004) research about the development of expertise by nurses is well-known. Benner tested an earlier model of adult skill acquisition produced by brothers Hubert and Stuart Dreyfus (H. L. Dreyfus, Dreyfus, & with Athanasiou, 1986; S. E. Dreyfus, 2004) which defined five stages of learning: novice, advanced beginner, competence, proficiency and finally, expertise. Overall, there is a “progression from the analytic behavior of a detached subject, consciously decomposing his environment into recognizable elements, and following abstract rules, to involved skilled behavior based on an accumulation of concrete experiences and the unconscious recognition of new situations as similar to whole remembered ones” (H. L. Dreyfus et al., 1986, p. 35). Benner’s research with nurses affirmed these stages and described the movement from novice graduates who followed rules inflexibly to those with expertise who responded to changing situations intuitively using the wisdom of experience (Benner, 2001/1984, 2004). Benner has also drawn attention to the importance of both technical skills and “situated actions” for nursing (which she refers to by Aristotle’s terms, techné and phronesis respectively) (Benner, 2004, p. 189). While techné can be formally taught, phronesis is acquired through experiential learning.

Common threads in this literature about expertise are that it develops over time with both formal teaching and experiential learning.

**Relationships between carers, health professionals and health services**

This section considers how relationships between carers, health professionals and health or social services may be framed and the differing expertise of each party.

Twigg (1989) proposed an early model of the relationship between social care agencies and carers. Carers could be viewed in three ways: as resources (assumed to be willing to provide care, with the primary focus being the patient’s needs), as co-workers (with some interest in the carer’s own needs in order that they could sustain the caring role) and as co-clients (with their own needs for support, although secondary to the
patient’s, and carefully managed to avoid overwhelming service resources) (Twigg, 1989). A fourth position of superseded carer was added later – here the emphasis was on maximising the patient’s independence, motivated by concern for either the patient or the carer (Twigg & Atkin, 1994).

Ward-Griffin and McKeever (2001; 2000) studied 23 Canadian dyads consisting of a family member and a community nurse caring for an older person at home. They too described four types of relationships which overlap with Twigg’s above: nurse-helper (nurses providing most care while the family member had a supportive role); worker-worker (nurses expecting family carers to take on more tasks and delegating work to them); manager-worker (increasing family care with decreasing nursing involvement, although oversight was maintained) and nurse-patient (some nurse concern for the carer’s own wellbeing, but primarily in order to sustain care for the patient). These relationships could change over time, but there was a strong expectation by the nurses that family members would care, limited negotiation of the carer’s roles and, as noted earlier, workload and health service funding imperatives for shifting care from professionals to family (Ward-Griffin, 2001; Ward-Griffin & McKeever, 2000). A study of English district nurses (Gerrish, 2008) similarly described assumptions and service constraints which led to transferring care to the family. That author recommended focusing support on the whole family rather than only the identified patient.

A further variation of Twigg’s model has been put forward by Guberman and Maheu (2002). They proposed that when considering ways to sustain adults requiring care within their families at home, homecare service providers could focus only on the dependent person (similar to Twigg’s ‘carer as resource’), on the family (as co-client, resource or partner, overlapping with Twigg’s carer as co-client and carer as co-worker categories) or on the whole community being collectively responsible for care (Guberman & Maheu, 2002).

The above models reflect on the ways service configuration influences carer-professional relationships. Moving to the level of therapeutic relationships, Hasselkus (1995) proposed a model of changing carer-health professional relationships in geriatric care, based on an ethnographic study of family carers of older people. In this model, health professionals were initially the dominant experts in care in the hospital setting. Around the time of discharge, power became more equally shared between health professionals and the family members who would continue care in the community.
Once care had been established at home, family carers had the predominant role of determining how care was managed, with limited professional input. The strengthening role of carers and, conversely, the diminishing role of health professionals could create tensions if health professionals perceived this as a move away from preferred medical models of care (Hasselkus, 1995). Tensions arising from differing health professional and carer perspectives were also noted in Ward-Griffin and McKeever’s (2000) study.

Another way to conceptualise carer-professionals relationships is as a partnership. In the chronic illness literature, Thorne and Paterson (1998) traced a shift in what were considered appropriate health care relationships from “client-as-patient” to “client-as-partner” (p. 173) over a 15 year period from 1980. A similar idea of partnership with carers has developed, particularly in the literature about parents as carers of disabled children (e.g. Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006; Fereday, Oster, & Darbyshire, 2010; Kasahara & Turnbull, 2005; McIntosh & Runciman, 2008). Components of partnership that have been identified include working together in the best interests of the child, positive professional attitudes towards the disabled child, professional competence, equality of the partners with mutual respect, trust and communication, empowerment of parents and support for parents (Blue-Banning et al., 2004; Denboba et al., 2006; Fereday et al., 2010; Kasahara & Turnbull, 2005; McIntosh & Runciman, 2008). An interesting difference in these studies was that advocacy by health professionals on behalf of families was appreciated by carers and demonstrated a working partnership (McIntosh & Runciman, 2008), while the need for parents to advocate with health professionals could signal the lack of an effective partnership (Fereday et al., 2010).

Another concept that is apparent in literature about the relationship between health professionals and carers is differing definitions of knowledge and expertise (Jayne Brown, Nolan, & Davies, 2001). Harvath et al. (1994), researching care for the elderly, found family carers had important, unique knowledge about the person they cared for, while nurses had generalisable knowledge and skills which were essential for care too. They referred to these two types of knowledge by the anthropological terms “local knowledge” and “cosmopolitan knowledge” respectively (Harvath et al., 1994, pp. 29-30).
Chapter summary and implications for research

Whilst there is a vast literature about family caring, that which specifically addresses the aspect of learning to manage technical health procedures is limited. Carers may have little choice about taking on such roles, given the lack of alternative services. Carers’ learning occurs in the context of existing family relationships and elicits emotional responses, particularly when procedures are painful or distressing for the care recipient.

From carers’ perspectives, initial formal training appears to be of variable quality and to focus on clinical skills rather than the broader context of incorporating care into family life. Following basic training, carers take on responsibility for managing a procedure at home, perhaps with limited further professional support. However, through their own ongoing experiential learning, carers may develop significant expertise. The expert carer has become a recent topic of interest in policy and research, although with little detail about the nature of their expertise or how it develops.

Literature by health professionals about teaching technical health procedures presents a contrasting picture of a more structured process tailored to the learner. Only one study was found which drew on an explicit learning theory (Foster, 1993). Once again the emphasis was on initial training although it was recognised that learning is a continuing process. A few studies have evaluated training programmes, with positive outcomes (although only one randomised, controlled trial was conducted), while assessments of carers’ learning and competence indicate mixed outcomes. Issues such as carers’ competence and patient safety highlight the uncertain interface between professional and lay care with regard to technical health procedures. The relationship between health professionals and carers also warrants additional exploration.

In light of the lack of research to date about carers managing technical health procedures (albeit this may be some of the most complex care expected of carers), this thesis aims to address that gap by exploring the experiences of family carers who undertake technical learning procedures at home and developing theory about their learning process. While literature by health professionals provides guidelines for what should be covered in teaching programmes for various technical health procedures, this thesis will strengthen the voice of carers by drawing on their experience of what happens in practice. Carers will also be able to reflect on the totality of their training
experience, not only the initial training phase which health professionals focus on, thus extending knowledge about the whole training process.

The next chapter will outline the study methodology and how it was applied in answering the research questions.
Chapter 3: Methodology

The methodology used for this thesis research was grounded theory. This chapter provides an overview of the methodology, both theoretically and as applied in this study. It begins with a short outline of the historical development of grounded theory. The essential features of the methodology are then explored under the headings of data sources and sampling, data analysis, literature review and theory development. Consideration is given to how grounded theory can be evaluated and utilised. Following this theoretical background, the remainder of the chapter sets out why the methodology was appropriate for this research and how it was applied in practice.

The development and philosophy of grounded theory

Grounded theory was developed by two sociologists, Barney Glaser and Anselm Strauss, who published their original, joint exposition of the methodology, The Discovery of Grounded Theory, in 1967. The co-founders came from divergent backgrounds which influenced their contributions: Glaser from the Columbia University traditions of positivism and quantitative methods and Strauss from University of Chicago pragmatism and symbolic interactionism (Charmaz, 2006; Strauss & Corbin, 1998a). Glaser’s emphases included the comparison of data, emergence of theory from data and identification of a basic social process while Strauss highlighted the importance of fieldwork, a belief in human agency to respond to problems, and meaning (created through interaction) as the basis for action (Glaser, 1978; Strauss & Corbin, 1998a).

Glaser and Strauss further explicated their methods separately, Glaser in his book Theoretical Sensitivity (1978) and Strauss in Qualitative Analysis for Social Scientists (1987). Strauss subsequently worked with Juliet Corbin and together they continued to develop their grounded theory procedures (Corbin & Strauss, 2008; Strauss & Corbin, 1998a; Strauss & Corbin, 1990). Meanwhile, Glaser claimed to remain true to the original method and rejected what he saw as Strauss and Corbin’s forcing of data (Glaser, 1992). Kathy Charmaz’s work has developed a third version of this methodology which she termed constructivist grounded theory (Charmaz, 1990, 2000, 2006, 2009). In addition, some feminist researchers have adopted and adapted the methodology (e.g. Keddy, Sims, & Stern, 1996; Wuest, 1995; Wuest & Merritt-Gray,
2001), and other researchers have extended grounded theory methods to arguably produce related methodologies – Schatzman’s Dimensional Analysis and Clarke’s Situational Analysis (Bowers & Schatzman, 2009; Clarke, 2009; Kools, McCarthy, Durham, & Robrecht, 1996; Schatzman, 1991).

Glaser and Strauss did not initially define the ontology and epistemology behind grounded theory. Others later labelled Glaser as positivist or post-positivist and Strauss and Corbin as post-positivist or constructivist (Åge, 2011; Annells, 1996; Charmaz, 2000; Hall & Callery, 2001; McCann & Clark, 2003; Mills, Bonner, & Francis, 2006). On the other hand, Stern and Porr (2011) declared Glaser and Strauss were “staunch anti-positivists” (p. 33) because the purpose of grounded theory is abstract explanation, while Strauss and Corbin themselves rejected the positivistic position on the basis that any theory is an interpretation (Strauss & Corbin, 1998b). Charmaz, while asserting grounded theory need not be related to a single epistemology, has been clear that epistemological viewpoints are important because, whether stated or not, they influence what data are collected and how the data are analysed (Charmaz, 2006, 2009). She defined her own position as constructivist, being based on an assumption that the researcher is intrinsically part of a study and does not discover theory but constructs it through interaction and interpretation (Charmaz, 2006). Thus constructivist grounded theory “… assumes a relativist epistemology, sees knowledge as socially produced, acknowledges multiple standpoints of both the research participants and the grounded theorist, and takes a reflexive stance toward our actions, situation, and participants in the field setting – and our analytic constructions of them” (Charmaz, 2009, p. 129). She has contrasted her view that researchers construct an understanding of data with the objectivist idea (generally associated with Glaser) of discovering meaning inherent in data (Charmaz, 2002).

**Grounded theory methodology**

There has been a lack of clarity as to whether grounded theory is an overarching research methodology and/or a set of methods (Tan, 2010). *The Discovery of Grounded Theory* did not mention methodology but focused instead on how the “general comparative method” was used for generating theory (Glaser & Strauss, 1967, p. 117). However, Glaser (1992) later described grounded theory as “a general methodology of analysis linked with data collection that uses a systematically applied set of methods”
(p. 16). Strauss and Corbin used both the terms methodology and methods, but their procedural approach focused on the latter (Corbin & Strauss, 2008; Strauss & Corbin, 1998a; Strauss & Corbin, 1990). According to Charmaz (2005), the term grounded theory “refers both to a method of inquiry and to the product of inquiry” (p. 507).

Glaser and Strauss (1967) classically described grounded theory as “the discovery of theory from data systematically obtained from social research” (p. 2). Strauss and Corbin (1998a) explained that, “In this method, data collection, analysis, and eventual theory stand in close relationship to one another…the researcher begins with an area of study and allows the theory to emerge from the data” (p. 12). Glaser (1998) emphasised the importance of elucidating the participants’ viewpoint so that the theory would be relevant to those involved. However, he considered the theoretical concepts were “abstract of time, place, and people” (Glaser, 2002, p. 25), in contrast to Strauss and Corbin whom he believed forced concepts by insisting they be linked with conditions such as time and place (Glaser, 2002).

Grounded theory focuses on processes to describe what is happening in the data. Glaser referred to finding underlying “basic social processes” which were either a “basic social psychological process” or a “basic social structural process” (Glaser, 1978, p. 102). However, as a theory-generating methodology, the purpose goes beyond simply describing a process to developing an explanation of what is going on, of how people respond to experiences and even predicting future actions (Corbin, 2011; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998a).

From her constructivist perspective, Charmaz rejected the idea of theory emerging from data and instead considered that, as researchers, “we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices” (Charmaz, 2006, p. 10). In addition, she argued theory need not necessarily seek to explain and predict, but could also be useful for gaining understanding of a phenomenon through the theorist’s interpretation of it: “Interpretive theories allow for indeterminacy rather than seek causality and give priority to showing patterns and connections rather than to linear reasoning” (Charmaz, 2006, p. 126).

Whatever their viewpoint, users of this methodology aim to produce theory rather than description. However, Thomas and James (2006) have challenged the usefulness of a qualitative methodology for producing theoretical explanation, asserting that the primary focus of qualitative research is interpretive understanding. The process
of theory development in a grounded theory study will be discussed further below at the end of the methods section.

**Methods**

Grounded theory has specific methods for sampling, coding and analysing data. While these are now discussed individually, it should be noted that they are not separate, sequential steps, but rather, a fundamental aspect of grounded theory is “[j]oint collection, coding, and analysis of data…[which] should blur and intertwine continually, from the beginning of an investigation to its end” (Glaser & Strauss, 1967, p. 43).

**Data sources and sampling**

While grounded theory has become known primarily as a qualitative approach, it was conceived as a methodology which could be used in both quantitative and qualitative research with many potential data sources (Glaser & Strauss, 1967). Indeed, Glaser declared, “All is data” (Glaser, 1998, p. 8; 2007).

A grounded theory study begins with sampling wherever “persons, places, and situations…will provide the greatest opportunity for discovery” (Strauss & Corbin, 1998a, p. 206). The first data are analysed and initial, tentative concepts and theoretical ideas are developed. These guide further sampling which is directed at expanding and deepening the nascent theory (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998a). Hence ongoing sampling is purposeful, based on its theoretical relevance for making further conceptual comparisons (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998a). The iterative process of data collection, analysis and further theoretical sampling continues until theoretical saturation is reached – that is, the point at which no new theoretical ideas are arising, categories have well-defined properties and the relationships between them are clear (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998a).

There is no fixed sample size for a grounded theory study; theoretical sampling and saturation determine the final number with an adequate sample judged “on the basis of how widely and diversely the analyst chose his groups for saturating categories according to the type of theory he wished to develop” (Glaser & Strauss, 1967, p. 63).
The sample will not be statistically representative as in a quantitative study, but conceptually representative: “Theoretical sampling results in an ideational sample, not a representative sample. It is about an area of interest, a conceptual about, not a numbered about” (Glaser, 1998, p. 159). Hence the theory may be applicable beyond its original situation to wherever else the concepts are relevant (Glaser, 1998).

There are different views about the stage in the research at which theoretical sampling should occur. For Glaser and Strauss, all sampling beyond initial data collection was theoretical (Glaser & Strauss, 1967; Strauss, 1987). On the other hand, Charmaz suggested taking time to find out what issues are important in the research (through wide preliminary sampling) before moving on to theoretical sampling; otherwise, she contended analysis may be forced and closed off prematurely (Charmaz, 1995, 2000).

The ideal of theoretical sampling may be limited by practical difficulties such as ethical requirements and the “interactional reciprocities and situational demands” of research relationships with participants and organisations (Charmaz, 2006, p. 10). Strauss and Corbin (1998a) noted that, “Realistically, the researcher might have to sample on the basis of what is available” (p. 210). However, they were confident differences would naturally arise in the collected data (even if it were not possible to purposely sample for them), enabling comparative analysis to proceed (Strauss & Corbin, 1998a). This leads us to considering how grounded theory analysis should be undertaken.

**Data analysis: coding and memoing**

Data analysis begins with coding. Coding, in both qualitative and quantitative analysis, is a way of sorting large amounts of data and grouping concepts therein. However, in grounded theory, coding moves beyond simple description or categorisation to a more abstract analytic interpretation of what is happening in the data and what that means (Charmaz, 2006).

It is in coding that the differences between versions of grounded theory are most apparent, although different uses of the same terminology create some confusion and imprecision (Bryant & Charmaz, 2007; Dey, 1999). Glaser (1978) distinguished between two types of codes: substantive and theoretical. “Substantive codes conceptualize the empirical substance of the area of research. Theoretical codes
conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into the theory” (Glaser, 1978, p. 55). Substantive coding begins with “open coding” which is “coding the data in every way possible” (Glaser, 1978, p. 56). Glaser (1978) suggested three basic questions for open coding: “What is this data a study of? ... What category does this incident indicate? ... What is actually happening in the data (what basic social psychological or structural process)?” (p. 57; italics in original). The emphasis is on action or process in the data rather than description, hence the recommendation to use gerunds (verbal noun forms such as ‘caring’) as codes (Charmaz, 2006; Glaser, 1978).

Once open codes are well developed, the Glaserian researcher should move to “selective coding” seeking the “core variable” of his or her theory around which all other categories cohere (Glaser, 1978, p. 61). Theoretical coding is then used to “weave the fractured story back together again” (Glaser, 1978, p. 72), which may be aided by reference to Glaser’s “coding families” (Glaser, 1978 ch. 4; 2005 ch. 2). Dey (1999) argued that the use of these pre-existing coding families meant core categories were chosen somewhat arbitrarily by the researcher more than discovered from the data, contra Glaser’s fundamental premise.

Strauss and Corbin (1998a) identified three stages of coding: open coding, axial coding and finally selective coding. Open coding involves looking closely at the data to identify concepts and their “properties” (characteristics) and “dimensions” (range of variations) (Strauss & Corbin, 1998a, p. 101). Groups of related concepts become categories and the purpose of axial coding is to relate categories to one another. This includes defining the connections between macro and micro conditions and consequences, which Strauss and Corbin’s “conditional/consequential matrix” is designed to assist (Strauss & Corbin, 1998a ch. 12). Lastly, “selective coding” is used to integrate the theory around a “central category” (Strauss & Corbin, 1998a ch. 10).

Glaser considered these techniques cumbersome, and claimed they produced “forced, preconceived, full conceptual description…not grounded theory” (Glaser, 1992, p. 3). He continued to emphasise “emergence and discovery, which comes from the constant comparative method of coding and analysis” (Glaser, 1992, p. 60). Stern (1994) described the difference between the two approaches thus: “Strauss, as he examines the data, stops at each word to ask, ‘What if?’ Glaser keeps his attention focused on the data and asks, ‘What do we have here?’ Strauss brings to bear every possible contingency that could relate to the data, whether it appears in the data or not.
Glaser focuses his attention on the data to allow the data to tell their own story” (p. 220; emphasis in the original).

Charmaz’s coding appears conceptually similar to Glaser’s, although she has utilised her own terminology: initial, focused and theoretical coding (Charmaz, 2006). While she has provided clear descriptions of each stage, these seem less prescriptive than Strauss and Corbin’s. As with the others, open coding according to Charmaz should consider as many ideas as possible in the data. Consistent with her philosophical position, Charmaz believes researchers create or construct their codes as they interact with the data and interpret participants’ meanings (Charmaz, 2006). Focused coding selects “the most significant or frequent initial codes to sort, synthesize, integrate, and organize large amounts of data” (Charmaz, 2006, p. 43), moving to a more analytic level. In her opinion, it was uncertain whether axial coding would help or hinder this process; she noted it might provide a useful technique but could also impose an analytic framework (Charmaz, 2006). Finally in Charmaz’s approach, theoretical coding is intended to define the relationships among codes and integrate the theory, though not necessarily with a single core category (Charmaz, 2000).

Some researchers have argued that it is important to understand the underlying philosophical differences between variants of the methodology and not muddle incongruent coding and analysis approaches (Birks, Chapman, & Francis, 2006; Duchscher & Morgan, 2004). Others have viewed grounded theory methods as guidelines which can be utilised flexibly (Hallberg, 2006) or have even gone so far as to propose a synthesis of multiple techniques (Eaves, 2001).

All grounded theorists would agree the basic method for coding is “constant comparison” of data (Glaser & Strauss, 1967, p. 102), which one research team has likened to the multiple patterns seen in a kaleidoscope (Dye, Schatz, Rosenberg, & Coleman, 2000). Comparisons can be made between events, different people, the same person at different points in time, and categories (Charmaz, 2000). The unit of comparison may vary from a single word to phrases, sentences, paragraphs, an overarching incident or even a whole document, depending on the density of ideas in the data and the analyst’s skill (Glaser, 1992; Strauss & Corbin, 1998a). Strauss and Corbin (1998a, p. 57) suggested “line-by-line” coding or “microanalysis” of about ten interviews during open coding to help generate many concepts. However, “Once categories are established, analysis becomes more focused on filling out those categories and verifying relationships” so coding can become more selective (Strauss &
Corbin, 1998a, p. 70). However, Dey (1999) considered this “partial coding” risked “theoretical sufficiency rather than saturation” (p. 257).

Codes are not pre-defined in grounded theory. They arise from the data and may be created by the researcher or taken from participants’ own words (in vivo codes). Charmaz (2006) described the generation of codes as “part work but it is also part play” (p. 70) as the researcher tries out ideas to see what best fits with the data. Strauss and Corbin (1998a) also highlighted the importance of the researcher’s creative thinking. Coding is flexible too: data may be coded in more than one way, previously coded material may later be recoded differently, and new categories may emerge late in the analysis and necessitate checking for further examples in other material (Charmaz, 1995, 2006; Glaser & Strauss, 1967).

Whatever the terminology, the successive levels of coding aim to abstract the data and move it to a more theoretical level. The resulting emphasis on patterns is a key feature of grounded theory, but the disconnection of events from their original context has been perceived by others (such as phenomenologists) as a weakness of the methodology (Alvesson & Sköldberg, 2000; Charmaz, 2006; Dey, 1999).

A key technique for progressing from coding to theory development is the use of memoing. Memos are not unique to grounded theory but they are an essential feature of this methodology (Lempert, 2007). Memos are “The researcher’s record of analysis, thoughts, interpretations, questions, and directions for further data collection” (Strauss & Corbin, 1998a, p. 110). Memos are commonly written but diagrams may also be used to explore relationships between concepts (Charmaz, 2006; Strauss & Corbin, 1998a). Most importantly, memos are not intended to describe data but to analyse and conceptualise them in the move to theory development (Lempert, 2007; Strauss & Corbin, 1998a). Subsequently, ordering or sorting memos clarifies and strengthens emerging theoretical ideas and memos can form the basis for writing up the eventual grounded theory (Charmaz, 2006; Glaser, 1978; Strauss & Corbin, 1998a).

**Literature review**

A discussion on the use of literature might have been expected earlier but has been left until this point, consistent with the classic grounded theory position that literature review need not, indeed should not, precede a study. According to Glaser, this stance was intended to prevent preconceived concepts being imported into the data and
inhibiting the discovery of new concepts from the data (Glaser, 1992). In addition, if the view is taken that concepts emerge from the data, it is not possible to pre-determine the relevant literature (Corbin & Strauss, 2008). However, once a grounded theory begins to develop, the researcher can refer to literature for comparison (Glaser, 1992, 1998).

Practically, researchers may already be aware of literature in their area of interest and some review is required in order to justify research funding proposals (Stern & Porr, 2011). Ignoring existing knowledge could also lead to “reinvention of the wheel” (Alvesson & Sköldberg, 2000, p. 17). Strauss and Corbin (1990) and Charmaz (2006) acknowledged existing literature could provide a starting point for research, but stressed one’s own data should then guide the developing theory.

Theory development

How does a researcher develop theoretical ideas? As already noted, Glaser and Strauss (1967) emphasised the emergence of theoretical ideas from data in contrast to deduction from a priori concepts, yet they also recognised the researcher is not a “tabula rasa” (p. 3). Indeed they wrote that, “The root sources of all significant theorizing is [sic] the sensitive insights of the observer himself” (1967, p. 251), adding that such insights could come suddenly or slowly, at work or play, from theory or without theory, from observing others or from self-reflexive thought, and early or late in the research process. However, elsewhere this theoretical sensitivity has appeared to be a more contentious issue in the differing versions of grounded theory. Glaser later wrote, “The first step in gaining theoretical sensitivity is to enter the research setting with as few predetermined ideas as possible…In this posture, the analyst is able to remain sensitive to the data by being able to record events and detect happenings without first having them filtered through and squared with pre-existing hypotheses and biases. His mandate is to remain open to what is actually happening” (Glaser, 1978, pp. 2-3). Somewhat contradictorily, he immediately added, “Sensitivity is necessarily increased by being steeped in the literature that deals with both the kinds of variables and their associated general ideas that will be used” (p. 3). Elsewhere Glaser again instructed researchers to suspend prior knowledge initially in a study while suggesting it might be useful later as a point of comparison during theory generation, without forcing data to fit one’s interests (Glaser, 1992, 1998).
Strauss and Corbin (1998a) suggested objectivity was desirable in research in order to produce “reasonable” and “impartial” findings (p. 53), but recognised complete objectivity was impossible and the more recent edition of their work acknowledged researcher subjectivity in analysis (Corbin & Strauss, 2008). They advised researchers to try to be aware of their prior knowledge and experience but “in ways that enhance the creative aspects of analysis rather than drive analysis” (Strauss & Corbin, 1998a, p. 59).

Charmaz believed researchers’ backgrounds inevitably sensitised them to initial concepts which needed to be confirmed in the field, but their task was to go beyond this and consider new theoretical interpretations in data analysis (Charmaz, 1990, 2005, 2006). Thus, sensitising concepts could provide a starting point rather than an endpoint (Charmaz, 1995, 2000, 2006) and researchers should be reflexive about how their presuppositions influenced the research process. Others have pointed out the naivety of believing investigators could begin from an atheoretical position or develop theoretical thinking de novo and have contended that they necessarily draw on existing knowledge and experience to generate ideas (Cutcliffe, 2005; Dey, 1999; Kelle, 2007).

Glaser and Strauss initially emphasised the inductive nature of grounded theory development, in contrast to the emphasis on deductive research prevalent at the time (Glaser & Strauss, 1967; Strauss & Corbin, 1998b). However, each recognised in their later writing that both induction and deduction are involved, the former in deriving initial concepts from data and the latter in hypothesising about where next to theoretically sample (Glaser, 1978, 1998; Strauss & Corbin, 1998a). Charmaz and others (Charmaz, 2006, 2009; Reichertz, 2007; Richardson & Kramer, 2006) discuss the additional use of abductive reasoning in grounded theory, which “…arises from experience, leads to logical but creative inferences, and invokes testing these inferences with hypotheses to arrive at a plausible theoretical explanation of experience” (Charmaz, 2009, p. 137). Abduction thus requires both rational thought as well as creative openness to new possibilities (Locke, 2007; Reichertz, 2007).

The iterative process of data collection and analysis in grounded theory eventually leads to the saturation of categories and development of a theory that is well-integrated and credibly accounts for what has been studied (Glaser & Strauss, 1967). Ultimately the aim of this methodology is a theory which meets four criteria: it fits the data without being forced, works (that is, provides a meaningful explanation of the situation that was studied), is relevant to those working in the area and can be modified
with new data (Glaser, 1978, 1992, 1998; Glaser & Strauss, 1967). The theory must be sufficiently general and flexible to be able to be applied to other or changing situations within the substantive area of study (Glaser & Strauss, 1967) and the openness to modification means a grounded theory can be corrected and adjusted as changes take place (Glaser, 1999).

**Evaluating and utilising grounded theory**

There has been much debate about how to evaluate qualitative research in general and more specifically, grounded theory. The traditional hallmarks of rigorous quantitative research are internal validity, external validity, reliability and objectivity (Guba & Lincoln, 1994). Some argue this terminology should be retained in qualitative research, although each paradigm uses different assessment strategies (e.g. Morse, Barrett, Mayan, Olson, & Spiers, 2002). Others have suggested alternative criteria: Guba and Lincoln (1994) proposed four “trustworthiness” criteria of credibility, transferability, dependability and confirmability (p. 114), intended to parallel the quantitative terms above. A number of other specific criteria have been suggested (e.g. Angen, 2000; Davies & Dodd, 2002; Patton, 2002; Whittemore, Chase, & Mandle, 2001). More broadly, Denzin and Lincoln (1994) have identified four positions on criteria for evaluating qualitative research: the positivist position of applying standard criteria to all research; the postpositivist position that qualitative research, as an alternative paradigm, requires distinctive evaluation criteria; the postmodern position that “the very idea of assessing qualitative research is antithetical to the nature of this research and the world it attempts to study” (p. 480); and the poststructuralist position that a completely new set of criteria need to be created, separate from positivist and postpositivist assumptions.

Similarly, various approaches have been proposed for evaluating grounded theory. As noted in the previous section, the initial benchmarks of a grounded theory, which Glaser continued to advocate, were “fit, work, relevance and modifiability” (Glaser, 1992, p. 15). Corbin and Strauss (1990) provided criteria for judging grounded theory in four areas: the validity, reliability and credibility of the data; the plausibility and value of the theory; the adequacy of the research process; and the empirical grounding of the research findings (Corbin & Strauss, 2008; Corbin & Strauss, 1990; Strauss & Corbin, 1998a; Strauss & Corbin, 1990). Charmaz detailed her criteria for
adequate grounded theory research under the headings of credibility, originality, resonance and usefulness (Charmaz, 2005, 2006). Other suggested frameworks for assessing rigour in grounded theory include evaluating the use of grounded theory methods, assessment of the theory produced, and an emphasis on reflexivity in research (Chiovitti & Piran, 2003; Hall & Callery, 2001; Wuest, 2012).

At this point, it is worth considering the question of truth in grounded theory and the related issue of verification. Glaser claimed the grounded theorist need not be concerned with “truth” or “reality” of data, its “accuracy” or “reproducibility” because the purpose of grounded theory is conceptualisation, which transcends the data it arises from (Glaser, 2007, pp. 1,2,5). Strauss and Corbin wrote that “Theories are interpretations made from given perspectives as adopted or researched by researchers” rather than “the formulation of some discovered aspect of a pre-existing reality ‘out there’” (Strauss & Corbin, 1998b, p. 171). As would be expected, Charmaz’s approach assumes ‘a’ rather than ‘the’ reality is constructed, yet she also claimed to take a realist approach because a constructivist grounded theory “addresses human realities and assumes the existence of real worlds” (Charmaz, 2000, p. 523). Nor does she adopt a radical subjectivist position, whereby “individual consciousness explains all” but instead contends, “Constructivist grounded theory aims to position the research relative to the social circumstances impinging on it” (Charmaz, 2009, p. 134). Lomborg and Kirkevold (2003) have also argued for a reconsidered realist position with regard to how a grounded theory fits with the empirical world.

Glaser and Strauss’s purpose in setting out their grounded theory method was to stimulate the development of theory, in part to counter the emphasis that existed at the time on verification of theory (Glaser & Strauss, 1967). The process of constant comparative analysis generated hypotheses which “are verified as much as possible in the course of the research” (Glaser & Strauss, 1967, p. 39). Strauss and Corbin continued to champion this position (Strauss, 1987; Strauss & Corbin, 1998b) while Glaser later rejected it: “These hypotheses are probability statements, not facts that are verified. Grounded theory is not verificational. Its statements are probabilities that are readily modifiable as new data emerge properties of categories [sic]” (Glaser, 1992, p. 29). Charmaz concurred: “Checking hunches and confirming emergent ideas, in my view, does not equal verification…Rather than contributing verified knowledge, I see grounded theorists as offering plausible accounts” (Charmaz, 2006).
Given these varied positions, what can be said about the generalisability and usefulness of a grounded theory? Its proponents argue its generalisability arises from its abstract conceptualisations which can then be applied in other relevant situations. Glaser (1992) took a broad view of applicability – wherever the theory could fit, work and be relevant – whereas Strauss and Corbin were more qualified in linking a theory to the specific conditions under which it was developed (Corbin & Strauss, 1990; Strauss & Corbin, 1998a, 1998b). Charmaz (2006) argued “situating grounded theories in their social, historical, local, and interactional contexts strengthens them” (p. 180) and allows comparisons that can in fact lead to more general theory. Each would agree a grounded theory can continue to be modified or qualified as new data become available and as societies change, although Charmaz questioned how often this happens in practice (Charmaz, 2006; Glaser, 1992; Strauss & Corbin, 1998b).

Having considered the theory of this methodology, we now move to a discussion of how it was used in this study, including why this approach was chosen, the place of reflexivity and literature review, data collection and analysis through to theory development.

From theory to practice: Applying grounded theory in this research

Choosing a grounded theory approach

Two questions guided this thesis: ‘What are the experiences of family carers who undertake technical health procedures at home?’ and, ‘How do professionals teach family members the necessary skills for such procedures, and what is the process of learning from carers’ perspectives?’ As the experience and process of learning to manage technical health procedures at home have not been well described in existing literature, it was appropriate to take an exploratory, qualitative approach in this research. In particular, grounded theory was an apposite methodology, fitting all three of Birks and Mills’ (2011) criteria for its usage: “Little is known about the area of study. The generation of theory with explanatory power is a desired outcome. An inherent process is embedded in the research situation that is likely to be explicated by grounded theory methods” (p. 16).

While there was little existing research on this topic, it was not unfamiliar to me. I have a disabled daughter and have learnt three technical health procedures in
caring for her. Indeed, my own experiences drove my curiosity to know what the experience was like for other carers and whether there was a common process of learning. At the same time, I began the project anxious lest I bias the research and therefore initially tried not to think about my own situation. However, reading Charmaz’s approach, I realised my background would inevitably shape my research process and rather than denying or ignoring this, it was better to acknowledge these influences and be open about their effects. I have done this by taking a reflexive approach – “This means that the researcher should constantly take stock of their actions and their role in the research process, and subject these to the same critical scrutiny as the rest of the ‘data’” (Mason, 1996, pp. 5-6). My reflexive journey is detailed in the section below.

Charmaz’s constructivist approach also resonated with the research questions. It seemed to me that the nature of individual experiences of learning and managing technical health procedures would necessarily be unique (a relativist ontology) and my seeking to understand them would involve interpretation and the co-construction of meaning with participants (a transactional/subjectivist epistemology) (Lincoln, Lynham, & Guba, 2011).

The reflexive journey

Right at the beginning of this research, six months before any data collection began, I took time to write about my own experiences with managing technical health procedures and reflect on the learning process I had gone through. A short summary of this is set out in the box below.
March-April, 2011

I would describe my experience of learning and undertaking technical health procedures as having three broad phases. In the initial stage of taking on something new, I felt anxious about doing things correctly and not hurting or harming my daughter, so I carefully followed the instructions I was given. There was also some stress in fitting additional care into existing family routines. Over the ensuing weeks and months, anxiety subsided as the procedure became familiar and competence and confidence increased. In this second phase, we began adapting procedures to fit in with our lives (such as doing things earlier or later than usual in order to go on an outing or when travelling) and realised some variation was possible without causing ill-effect. Finally, the procedures became ordinary for us and are simply part of what we do, although I am still aware at times of being different, particularly when not in our home environment.

In all three instances, I had teaching from district nurses in our home showing and explaining the procedure then supervising my practising it, with some written material for reference. I was mostly responsible for in turn teaching my husband (because he wasn’t usually at home in the daytime when the teaching took place). There was good initial professional support, which reduced when the nurses presumably felt we were managing well. However, I have had ongoing phone contact when needed (such as when a problem arose) and sometimes further home visits for assistance. In addition, on occasions I have utilised the internet and networking with other carers to problem-solve.

Two of the procedures are ongoing. In the case of the third, it proved difficult and added a lot of work but did not produce the hoped-for benefit. In this case, I chose to stop doing it and we returned to our previous management which, while not ‘ideal’, was ‘good-enough’. In this case, there was some choice because there was an alternative; but my ‘choice’ to care is generally constrained by a lack of other options (family or professional).

Over the years, in addition to my husband, I have taught I think three other non-family members to do one of the procedures. In each case, I noticed their initial anxiety and concern to do things right, and the need for support and encouragement, gradually progressing to competence and confidence. In the case of two of the procedures, I have also been involved in teaching my daughter to self-manage her own care and my involvement has consequently reduced.
Clearly I came to this research as an ‘insider’ – or did I? Certainly I have drawn on my own experiences of caring and deliberately aligned myself as being another carer when seeking participants (by mentioning this in my information sheet) in the hope this would give people a sense I was not an alien researcher but had some understanding of their situation. When explaining the research before beginning interviews, I mentioned my interest in the topic was in part due to having a disabled daughter and would give other brief information about my situation if asked. At the same time, I had no experience and limited understanding of many of the procedures other people were undertaking, so could be viewed as an ‘outsider’. I also drew on other aspects of my identity during the study – my information sheet referred to my experience doing part-time research work for several years (intended to engender confidence I was not a young novice) and when seeking the assistance of professionals to help with recruitment, I sometimes mentioned my past medical background (in an attempt to allay any fears I would harm their patients). Of course those I interacted with will have had their own perceptions of my identity. Overall, I could be viewed as both an insider and an outsider at different times. Merton (1972), Mullings (1999) and Srivastava (2006) agree that being an insider or outsider is not a binary either/or, or fixed state, but rather, researchers (and others) adopt multiple and fluid identities which are constantly negotiated in the course of social interaction.

Undoubtedly I have both consciously and unconsciously filtered and understood participants’ information through the lens of my own experience, but I have tried hard to hear their voices rather than imposing my own. I found each interview had surprises and puzzles, and rather than simply confirming my pre-existing beliefs, these were instead challenged by the differences. The concept of ‘embracing care’ in particular struck me initially because it seemed so contrary to my own experience; it was only as the full range of positions within the spectrum of embracing care was developed from the data that I could see where my story fitted. In terms of the learning process, the grounded theory ultimately presented in this thesis does have parallels with my experience as outlined above. Having written my own story initially then put it aside, I was surprised to find how well it fitted the eventual findings after I had written them up almost two years later and returned to compare them with my earlier thoughts. My experience had provided theoretical sensitivity but nonetheless, the learning process described through this research was developed from the participants’ data and adds
considerable depth and variation to the stages beyond my original sketch. In addition, the excellent support of my supervisors and mentor provided a very important check for the research. In particular, discussion of the analytic process and emerging theoretical concepts was very helpful for confirming the rigour of the research procedures and refining the findings.

**Literature review**

I did an initial, limited literature review in order to develop a research proposal and scholarship application. This was followed by a larger, more methodical review when I began my study, focused on carers learning to manage technical health procedures, to clarify what was already known and confirm there was a gap in knowledge which this research could address. This review was updated later in the study with literature which had been more recently published.

In the course of data collection and analysis, I began reading about other topics that arose from the research and as the findings evolved, they directed further searches for literature relevant to the emergent themes. Other subjects that were explored (not all of which were ultimately relevant) included carer-professional relationships and partnerships; chronic conditions self-management; choice for carers; ethics of care; normalisation; complex care co-ordination; health literacy; experience-based design, Rogers’ diffusion of innovations theory; Bandura’s learning theory; Prochaska’s transtheoretical model of health behaviour change; and the development of expertise.

In writing this thesis, the literature has already been outlined (incorporating material reviewed throughout the study) in order to provide background to the research subject. Following the presentation of the findings, these are discussed in the light of this literature.

**Data collection**

**Data sources**

Interviews were chosen as the best way to collect data about carers’ experiences in this study. Interviews with relevant informants are a well-recognised method of data collection in qualitative studies generally and in grounded theory specifically, providing
the opportunity to draw on participants’ in-depth, experiential knowledge of a topic (Charmaz, 2002, 2006).

The possibility of adding observational data was considered but discounted because of the added ethical issues - this would have involved observing carers performing procedures on another person whose additional consent would also be needed (which could be problematic in the case of children and other vulnerable participants) and some procedures would involve private parts of the body. For similar reasons, photo elicitation techniques were not used.

Interviews with carers managing technical health procedures were the initial source of data. A second round of interviews was then conducted with health professionals who had a role in training carers, in order to shed further light on the teaching/learning process.

Some carers showed me written materials they had been provided with in their training and I was also able to obtain some resources used by health professionals. These materials were utilised as additional data and analysed and incorporated as the grounded theory developed.

**Ethics**

Separate ethical approval was sought for each phase of this study, in both cases from the Multi-region Committee of the New Zealand Health and Disability Ethics Committees, in order that participants could be recruited from throughout New Zealand. Both stages were approved with minor or no required changes, respectively (carers’ study reference MEC/11/EXP/076 and health professionals MEC/12/047; see appendices A and B). Formal ethical approval processes were also required (and satisfactorily completed) by three organisations through which I sought to recruit. In addition, I liaised informally with a variety of carers’ organisations.

One-off interviews were sought to avoid overburdening busy carers and health professionals. Carers were recruited via a third party (carer organisations and nurses) passing on information about the study. They were given my contact details or, with their permission, I was given their name and phone number. Initial contact was by phone or e-mail, when I explained the study, answered questions and ensured the person received a copy of the information sheet (see appendix C). If the person was willing to be interviewed, this was then arranged. Care recipients were not included in
the interviews, both because the study focused on the carers’ perspective and to reduce the potential for harming the care relationship.

Health professionals were recruited by approaching managers or leaders of relevant services to ask if they would pass on information about the study to staff (see appendix D). Those who were interested in taking part could then contact me directly. Some snowballing was also used to identify other relevant participants.

At interviews, I again explained the study and invited questions before getting written consent and permission to tape-record, then proceeding with the interview. Consent forms are set out in appendices E and F, and the demographic data collection forms which were used are in appendices G and H.

**Sampling and conduct of interviews**

My initial aim was to sample a broad spectrum of family carers in a range of situations I imagined could influence their experience of learning to manage a technical health procedure. Thus I hoped to interview people managing a variety of procedures; people caring for their child, spouse or parent; both males and females and carers from different ethnic groups; those caring short and long-term, both early and later in their experience; and people living in main centres as well as areas further from secondary or tertiary health services.

Interviews with carers took place from November 2011 through to September 2012. A total of 28 carers expressed interest in the study; one chose not to proceed to an interview; one I declined as he was not managing any technical health procedure; and four were put on hold as saturation appeared to be nearing (none of these was subsequently interviewed). This resulted in 22 interviews, four of which involved two carers (three sets of parents and a mother-daughter pair). Other than advising the organisations I sought to recruit through that I was looking for a diverse range of participants, I had little ability to direct the sampling. However, the final sample did include diverse experiences encompassing all the hoped-for variation and enabling comparative analysis. (The participants and their context are detailed in part II of chapter 4.) While theoretical sampling was not possible, I did explore emergent theoretical ideas with subsequent participants and the final sample eventually provided participants representing all the theoretical characteristics I would have sought (for example, all the positions within the spectrum of embracing care).
All the carers chose to be interviewed in their own homes. Interviews lasted from 30 minutes to two hours (average just under an hour). Participants were given a $25 gift voucher at the conclusion of the interview to thank them for their time and contribution.

Where possible, the scheduling of interviews was staggered to allow time for initial analysis of each interview before proceeding with the next. However, the timing was also influenced by what was convenient for participants and, when significant travel was required, the pragmatic need to conduct up to three interviews in the same area over one to three days.

Saturation was close by the seventeenth interview, but five further interviews were already planned and went ahead. These confirmed existing theoretical constructs and, while rounding them out and providing some excellent additional examples, they did not add further new concepts. Saturation of the carers’ data was considered complete at this point.

When beginning the second round of interviews, with health professionals, I again had some ideas about an ideal range of participants, in line with the kinds of teachers the carers had identified. These included people teaching each of the technical health procedures managed by the carers; both specialist and generalist staff; and those teaching carers of children as well as carers of adults. It was easier to identify where to sample relevant health professionals and find appropriate services to approach, but this did not mean all chose to take part. However, with perseverance, a good variety of participants was achieved and saturation was reached after 12 interviews (with a total of 15 interviewees), as again evidenced by the lack of new ideas arising from the data.

The interviews with health professionals were undertaken between February and September 2013. All took place at or close to the participants’ workplaces. They lasted from 46 minutes to 1.5 hours (average just under an hour). Participants were once again offered a $25 gift voucher at the conclusion of the interview in recognition of their involvement in the study.

Initial interview schedules were developed for each group with broad general questions about the experience of managing a technical health procedure and the process of learning (see appendices I and J). After each interview was analysed, questions were added and refined in order to investigate nascent theoretical ideas (these additions are also annotated in appendices I and J). The health professionals’ interview schedule was also influenced by emerging ideas from the earlier interviews with carers.
As this study sought to explicate the experience and learning of carers, they were interviewed first in order to focus on their views. The health professionals then provided further detail about their teaching and what they observed about the learning process of carers. They were also able to confirm and expand on some aspects of the concept of embracing care which had arisen from the carers’ interviews.

Data analysis

Transcription and use of quotations

Glaser (1998) eschewed taping interviews and worked from field notes, confident that “The mind is a sponge. It does not forget anything.... What is missed will be remembered when relevant” (Glaser, 1998, p. 110). I am less confident in my memory, and also find trying to take notes while interviewing inhibits my attention to the speaker, so I chose to tape interviews and transcribe them. When a new code was created at a later point in analysis, or when something initially considered unimportant appeared more relevant sometime afterwards, transcripts also offered the opportunity to return to earlier interviews to search for other instances; field notes alone might have lacked the detail needed for such later review.

All participants agreed to have their interview recorded bar one family carer (for whom I took notes). I transcribed all the interviews myself and offered participants the choice of receiving a copy to review; 23 chose to do this, of whom only one requested minor corrections.

In presenting the findings in the following chapter, quotations from participants have been used to illustrate the points made. The speakers have been identified as family carers (FC) or health professionals (HP) together with an interview number. When there were two participants in an interview, they have the same interview number and are distinguished by the addition of A or B. In order to reduce the risk of participants being identifiable, further details about the speakers have not been added (except where necessary for clarity); combined demographic and contextual information about the two groups has been provided in section II of the findings chapter.

The interviews were transcribed as closely as possible to the original spoken language, including repetitions and broken or interrupted sentences. In converting oral
speech to written text, punctuation has been added to fit the oral cues (such as pauses) and to help the reader make sense of the dialogue. An ellipsis (…) signifies a word or words have been omitted to shorten a quote for presentation. Square brackets [ ] indicate the words within them were not present in the original conversation but have been added, either for clarity or to replace identifying features such as names and places. Words have been underlined where the speech was clearly emphatic.

**Coding, memoing and theory development.**

Data collection, coding and analysis were intertwined and iterative processes throughout this research. Initial detailed attention to the transcripts developed many codes which were later grouped into higher level categories as theoretical ideas emerged.

I began coding from the first interview. I coded units of sense, which could be a single sentence to one or more paragraphs on the same topic. My initial codes were simply a word or phrase that best seemed to capture the meaning of a segment of data. Some initial codes were quite descriptive (‘equipment supplies’), some were in vivo terms (‘and then’) and where possible, I tried to use gerunds to create active phrases (‘becoming expert’). Material was coded in more than one way where it seemed to contain more than one idea. I used NVivo software to assist in managing my coding, creating a ‘free node’ for each new code.

As subsequent interviews were coded, new examples within each code were compared with existing material for similarities and differences, along with considering why these were occurring. Additional codes were added for new concepts that arose, some codes were renamed, overlapping codes were condensed while others were subdivided for more detail. Relationships between codes were noted and memos were written for each code.

After the eighth interview, I began attempting to group codes using small cards and a whiteboard and writing a rough, initial storyline (Strauss & Corbin, 1998a). Further interviewing, coding and discussion with my supervisors led to rearranging and further developing groups of codes. Memos were then written about the developing theoretical ideas. Preparing an abstract and then material for a poster (after 13 interviews) to present at a research forum gave me the opportunity to clarify my thinking about the concept of embracing care (see appendix K for presentation
abstracts). A departmental presentation three months later provided further feedback on this concept as well as an initial outline of ‘novice’ and ‘expert’ carers. More detailed analysis of all the codes and rewriting of theoretical ideas were done after the family carer interviews were completed. I also recoded line-by-line one of the later family carer interviews in order to ensure I had not become blinkered by the theoretical ideas that had been developed and was therefore overlooking other concepts; however, this did not result in any significant new codes.

When I began interviewing health professionals, I decided to code these de novo rather than use the existing family carer codes, in order to be open to hearing a different story from these participants rather than assuming it would match the carers’ account. However, my existing knowledge undoubtedly influenced how I thought about the new interviews. It was also quickly apparent that much of the health professionals’ description of their teaching process mirrored what family carers had told me and that some identical codes were appropriate. For example, there was a clear instance of a carer ‘resisting embrace’ in the first health professional interview and examples of all the other positions I had defined within the spectrum of embracing care were given in subsequent interviews, both spontaneously and in response to more focused questioning on this topic. The health professionals were also able to add some further details which would be less likely to be volunteered by carers, such as situations of people neglecting to care. Thus this second round of interviews completed saturation of concepts.

However, I was disappointed the health professionals did not add as much clarity as I had hoped to the process of how carers moved from novice to expert. Instead, they provided a lot of detail about their initial teaching. Despite extensively coding and memoing this material, it seemed to remain at a descriptive rather than theoretical level in my analysis and I came to a halt, feeling stuck. A joint brainstorming session with my supervisors at this point was very helpful as we reconsidered all the health professional codes to see whether or not they could be integrated into my existing schema. It was then apparent the health professionals were indeed providing information about the earliest stage of the carers’ learning process as this was the focal point of their teaching, while the carers’ ongoing experience managing technical health procedures (with greatly reduced health professional input) highlighted their developing expertise. Two further health professional interviews after this time confirmed there were no new concepts arising and data collection was complete. Thereafter, the separate family carer and health professional data and memos
were further analysed jointly and the grounded theory presented in this thesis was written up.

The two component processes of learning to manage a technical health procedure and embracing care were by now well-developed, but I continued to struggle with finding an overarching core concept. Further discussion with my supervisors along with returning to the data and thinking about the basic grounded theory question of “What is going on here?” (Charmaz, 1995; Glaser, 1978; Strauss & Corbin, 1998a) eventually resulted in the development of ‘wayfinding’ as the central concept.

At the same time as writing up the final findings, I re-read all the transcripts. Having been working with small, fractured pieces of the interviews, I wanted to confirm that the theoretical ideas I had developed did indeed fit the whole accounts participants had given. I found they could be read and made sense of in the light of the grounded theory presented here, as could my own experiences. At this time, a short summary of the research findings (see appendix L) was also sent to all the participants who had requested this. They were offered the opportunity to discuss the findings or give feedback to myself or my supervisors if they wished. Only one family carer emailed a brief response (“I thought that it was very well written and very accurate”) and two health professionals sent short email comments (“Interesting reading” and “I think you have captured the essence and diversity of the topic”).

Summary

The purpose of grounded theory is to produce theoretical understandings about processes related to the topic of enquiry. Data collection, coding and analysis are intertwined procedures which help develop concepts at successively more abstract levels. This culminates in a theory which, while grounded in its original data, moves beyond description to explaining what is happening in the area of interest. These interpretive accounts can be applied in other relevant situations while remaining open to modification in the light of new data.

Three main versions of grounded theory are now recognised, distinguished by differences in their underlying ontology and epistemology as well as some variations in procedures. Glaserian grounded theory is generally positioned at the positivist end of the research spectrum and seeks to discover the participants’ underlying reality. Strauss and Corbin have been seen as postpositivist and their hallmark is a detailed set of steps
to guide the researcher. Charmaz was the developer of constructivist grounded theory which, as its name suggests, assumes the inherent involvement of a researcher in creating rather than finding a plausible interpretation of the sphere of study.

Grounded theory was an appropriate methodology for a study seeking to explore the learning process of carers who manage technical health procedures. Given my own prior experience in this topic, Charmaz’s constructivist approach was apposite and it was important to be reflexive throughout.

Data for the research were collected from interviews with family carers and health professionals. Through the iterative analytic processes of coding, memoing, further interviews and eventual grouping of concepts, the grounded theory of wayfinding has been developed, comprising the two processes of carers’ learning and embracing care. In the next chapter, the substantive findings related to these theoretical concepts will be presented in detail.
Chapter 4: Findings

Wayfinding: The process and experience of learning to manage technical health procedures at home

This chapter presents the findings from this research, beginning with an overview of the grounded theory of wayfinding which describes the process and experience of family carers learning to manage technical health procedures at home. Following a brief description of the participants and their context, the remainder of the chapter details the two component processes which comprise wayfinding, namely the learning process and the process of embracing care, concluding with the linkages between them.

I. Wayfinding: A grounded theory

The overall experience of living with and learning to manage technical health procedures can be described as ‘wayfinding.’ This core concept originated from a family carer’s description of dealing with the difficulties posed by a new procedure as “finding your way through” (FC18). This expression epitomised all the carers’ stories and hence provided the overarching theoretical framework for the remainder of the findings.

Finding your way through was an active process. Although all carers were provided with some health professional support for learning and ongoing management of technical health procedures, carers interacted with those formal resources, applying and moulding them to their unique home care situations. When problems arose, they worked to find answers that were realistic in their life context. As ‘your’ way suggests, alternatives had to be considered and there were no one-size-fits-all solutions; rather, basic principles and generic fixes had to be adapted and refined for individual situations and idiosyncrasies. ‘Through’ reflects lived experience – this was no theoretical exercise but a practical response to the events of life which encompassed disability or chronic conditions. The phrase and features of ‘finding your way through’ have been encapsulated by the term ‘wayfinding.’

The motivation for wayfinding was to achieve good care and a good life for the recipient. This was well-expressed by one participant, who said, “It’s not about you as a
parent; it’s about the one you’re caring for. It’s about giving them better life, or better opportunities or better standard of care or more love” (FC20). This highlights the relational context of family care.

Wayfinding comprised two major processes. The first of these was the carers’ learning process, which began with a period of training for the procedure(s) they were going to manage. Health professional input was focused on this stage and provided an initial map for the new travellers. This was important for carers finding their bearings in an unfamiliar place. As the learning journey continued, ‘novice carers’ took responsibility for managing procedures at home. Professional support was still important at this point but carers also began to discover that variant routes existed while some territory was uncharted, necessitating the quest to find one’s own way through. With sufficient time and experience, carers reached a third phase of learning, in which they became ‘expert carers.’ At this point, carers were very much in charge of their own learning and problem-solving. While they still sought professional advice at times (especially for clinical issues) they also experimented with their own solutions and made use of other sources of information (particularly regarding practical management issues, such as how to get out and about with equipment in tow). Drawing on their experience and having an intimate knowledge of the recipient’s needs and responses meant expert carers could deliver highly individualised care, tailored to their home and family life context. Further detail about the learning process is given in section III of this chapter.

A second process termed ‘embracing care’ contributed to wayfinding. Embracing care was a reaction to the experience of managing technical health procedures. Managing these procedures involved an emotional response as well as a process of learning skills and knowledge. In this regard, embracing care sometimes meant accepting the situation and finding practical ways to manage it (which could also necessitate letting go of other expectations). However, sometimes it meant resisting the proffered solutions and seeking others, or only reluctantly agreeing to do what seemed to have to be done. At other times, the best way through for the carer, the recipient or both was to relinquish aspects of caring, either short-term or for good. Becoming overwhelmed by caring demands necessitated finding support to cope with and resolve temporary difficulties or a better way for the carer to manage an ongoing situation. These five positions of embracing care (accepting, resisting, reluctance, relinquishing
and overwhelmed) were not static and carers commonly moved between them at
different points in time. They will be further explicated in section IV of this chapter.

While the focus of wayfinding in this study was on the management of technical
health procedures, it was clearly part of the broader journey of adjusting to the whole
experience of living with disability or a chronic condition within the family. With this
in mind, the next section describes the two groups of participants (family carers and
health professionals) and provides an outline of their contexts.
II. The participants and their context

Family carers

In total, 22 interviews were undertaken with family carers. Four of these interviews involved two participants (three sets of parents and a mother/daughter pair), making 26 interviewees altogether. Of these, 21 were female and five male. Eleven of the carers were aged less than 40 years, 13 were 40-65 years old and two were over 65. The majority (18) identified themselves as New Zealand European; two as New Zealander; two Samoan; one Māori and four of other ethnicities (one person belonged to two ethnic groups). Eighteen lived in a main urban centre, four in a secondary urban centre and four in rural areas. Twelve had to travel beyond their home location to access secondary and/or tertiary health services for their family member.

Most participants (20) were managing technical health procedures for their child (in one case, two children); three for a partner; two for a parent and one for a grandparent. Those they cared for ranged in age from under five years (5), 5-18 years (13), 19-65 years (4) and over 65 years (5).

These carers managed a wide range of technical health procedures, as shown in Table 1. Just over half (14) of the carers had managed more than one procedure, either concurrently or sequentially, as shown in Table 2. Three carers had been managing a technical health procedure for less than one year; 12 for between one and five years; and nine for over five years (in two cases, the duration was unclear). However, other aspects of care such as feeding or personal cares commonly preceded the introduction of a technical health procedure or continued even if the technical aspect of care ceased. The longest duration of overall caring was 29 years.
Table 1: Technical health procedures

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Number of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastrostomy and/or jejunostomy feeding (PEG/MicKey button/PEJ)</td>
<td>12</td>
</tr>
<tr>
<td>Nasogastric or orogastric feeding</td>
<td>9</td>
</tr>
<tr>
<td>Type 1 or 2 diabetes management</td>
<td>7</td>
</tr>
<tr>
<td>Enemas or bowel washouts</td>
<td>5</td>
</tr>
<tr>
<td>Urinary catheter management (indwelling or clean intermittent catheterisation)</td>
<td>5</td>
</tr>
<tr>
<td>Portacath (central venous access line)</td>
<td>3</td>
</tr>
<tr>
<td>Suctioning (without a tracheostomy)</td>
<td>3</td>
</tr>
<tr>
<td>Injections (other than for diabetes)</td>
<td>3</td>
</tr>
<tr>
<td>Tracheostomy management (also included suctioning)</td>
<td>1</td>
</tr>
<tr>
<td>Peritoneal dialysis</td>
<td>1</td>
</tr>
<tr>
<td>Ileostomy management</td>
<td>1</td>
</tr>
<tr>
<td>Continuous positive airways pressure (CPAP) machine</td>
<td>1</td>
</tr>
<tr>
<td>Wound dressings (other than associated with any other procedure above)</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total procedures managed</strong></td>
<td><strong>52</strong></td>
</tr>
</tbody>
</table>

Table 2: Number of procedures managed by carers

<table>
<thead>
<tr>
<th>Number of procedures managed</th>
<th>Number of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
</tr>
</tbody>
</table>
The frequency of procedures varied according to need, from intermittently giving ‘as required’ medication by injection, to weekly irrigation of an indwelling catheter, to a daily bowel washout, several times daily cares (such as peritoneal dialysis, type 1 diabetes management, intermittent urinary catheterisation, bolus nasogastric feeds or suctioning) through to continuous activity such as managing a 24-hour feeding pump. The time taken to perform a procedure ranged from “one minute, two minutes” (an injection) to “two hours” (a central line infusion). Beyond the defined procedure time, carers remained alert to potential problems and available for additional care as required, including through the night. Eight participants regularly managed care during the night. Four of these accepted the need to do this and spoke of adjusting to such demands, although two also acknowledged the impact on their own health:

Most nights, I would be up probably two or three times to her, but some nights it can be eight or ten times ... for a suction or a reposition ... so I’m really only getting five to six hours sleep a night and that’s broken, but I’m just astounded how the body adjusts, because there’s no other options ... It was hard in the early days, but now I just don’t care (FC14).

I went to the doctor and I had really high blood pressure ... and then the doctor asked me about sleeping and I said, “Well you know, I don’t really sleep. I do sleep, I have to sleep, obviously I sleep, but it feels like I’m up, I nap ... The doctor explained to me, “You can’t keep going like that. Your brain – you need to have a decent amount of sleep. Your brain needs to reset itself” (FC19).

In contrast, broken sleep had been the impetus for two carers to problem-solve and find alternatives that reduced the likelihood of night-time interruptions and improved everyone’s rest. The last couple recalled a period of intense care for a very sick child, when they took turns to work in “four hour shifts,” as being a “nightmare time” when they were “absolutely beyond exhaustion. We were zombies” (FC20A). The reference to shift work draws a comparison with professional staff such as nurses. However, unlike professionals, family carers do not have regulated employment conditions like maximum hours of work or mandated breaks.

Learning to live with a chronic condition or disability could be described as entering a “different world” (FC7). For the participants, there were three pathways into this new world: the birth of a child with anticipated or unexpected health needs; sudden illness or accident; or the slow development of a chronic condition. Some carers assisted from the outset, while others gradually become involved with a person who
had self-managed initially but later required help. In adjusting to a new and often unexpected reality, some carers spoke also about grieving for the loss of the old or what had been anticipated.

Many carers had developed a new circle of peers in similar situations but at the same time, some found they lost old friendships through lack of time or because others could not cope with their new circumstances. Carers also had to deal with societal attitudes and reactions to their situation. While one mother had found that “most people are actually really quite kind” (FC14) another had struggled at times with “the sort of sympathy that we got, the pity, really, from other people” (FC18).

A variety of health and social services personnel entered not only the patient’s life, but often the family and their home too. Thus other members of the family inevitably became involved with the patient’s condition. In addition, some participants reflected their association with the health condition and their involvement in caring by their use of the plural, such as “It is our family’s disease” (9B), “We had a blockage of the portacath” (FC4) or “We were on antibiotics” (FC14).

While all the participants in this study had some degree of routine organisation of their caring, they also had to remain flexible and adaptable in response to changing health needs or family circumstances. In addition, they lived with uncertainty about the future. While some were hopeful of future health improvements for the care recipient or that the person would learn to self-manage, others had some anxiety about how ongoing care would be managed or were facing their loved one’s decline and death. Relative stability might be upset by an apparently ‘small’ incident (such as a stubbed toe taking a long time to heal because of diabetes and in turn, altering the diabetes control). Sometimes changing health circumstances were positive too, reflected for instance in reduced frequency of hospital admissions.

For me personally, I can’t think about the future because I actually, it’s too, it’s too scary ... so I don’t think about when she’s 18 or 20 or where she’s going to university. But then, it might be okay then, because I’ll know how she’s coping with herself and it might be easy. But you can only look to the future with what you’ve got now, and at the moment, it’s like “Whoa” (FC9A).

Now it’s come to the point where we know that she needs to have another form of feeding, that we can’t keep using the NG as a long-term solution. And with the PEG, it’s not going to be something that is probably long-term; we will eventually wean her off it, but we need time and we don’t want the stress and we need the backup so we can
slowly wean her off. And it may take one year, it may take five, but we know that the future holds that she won’t need it forever (FC5).

Finally, it should be reiterated that although the focus of this research was on caring for technical health procedures, this was often only a part of the care being given and of the whole family life context. In some instances, the procedure appeared relatively simple and a small part of the overall health needs of the care recipient, while for others, highly complex and critical procedures were a central part of care. However, the impact of procedures could not be simply categorised by the medical complexity. For example, one of the caring situations which seemed to me most complex (involving four procedures essential to sustain the child’s life) was presented by the child’s mother as quite straightforward to manage – “I don’t think it’s too bad” – and viewed in the context of enabling her child to live and the mutual pleasure of their relationship. On the other hand, possibly the least technically complex procedure (weekly irrigation of a urinary catheter) was part of 30 years of caring for a spouse with multiple (and now terminal) health conditions, with the participant’s tears at one point in the interview clearly reflecting her stress. Although the grounded theory developed from this study is presented in an abstract form, I hope the reader will remain cognisant that it was derived from the participants’ lived experiences. I remain grateful to all the family carers who shared their stories and wisdom with me and allowed me to briefly enter their homes and lives.

**Health professionals**

There were 12 interviews with a total of 15 health professionals (three interviews with pairs of participants), of whom 14 were female and one male. Four were aged less than 40 years and 11 were 40-65 years old. Most (13) were New Zealand European; one New Zealander; one Māori; and one other ethnicity (one person identified with two ethnic groups). Their professional roles were nurse (12), dietitian (two) and occupational therapist (one). Two were between five and ten years post-graduation; two were 11-20 years post-graduation; and 11 had graduated 20 years or more earlier. Two-thirds of the group (10) had post-graduate qualifications.

Between them, the health professional participants had taught all the types of technical health procedures managed by the family carer group. Six worked in the community while the remainder (nine) worked across inpatient, outpatient and
community settings (with varying degrees of focus). Eight had some specialisation in particular health conditions (and procedures associated with these) while seven were generalists. Five worked with adults, six with children and four with all ages. Two had experience as respite carers, thus bridging the experience of both health professionals and family carers.

Three participants spoke of doing some post-graduation training or professional development related to teaching, but most said they had not had formal training to teach as part of their base education. Rather, their teaching skills had been learnt “on the job” (HP6) through their own “common sense” (HP2) as well as with peer support and role modelling by senior staff.
III. The process of learning to manage technical health procedures

This section describes how carers learnt to manage technical health procedures. There were typically three phases in this process, beginning with an initial period of training until the carer reached the point of being able to manage at home. Next, novice carers continued learning and adjusting to their new role. They might require ongoing professional support, especially with managing any problems that arose. Later, with time and experience, carers could ultimately become expert managers of particular procedures with an intimate knowledge of the recipient’s needs and responses.

Meanwhile, as carers’ competence increased, the involvement of health professionals decreased, but their back-up support and expertise were still valued by carers, particularly if there were difficulties. Ideally, through the learning process, carers and professionals developed a working partnership for the benefit of the patient.

Reflecting their differing roles and experiences, the detail of health professionals’ interviews was more focused on the initial phase of teaching and on the clinical aspects of a procedure which needed to be taught, whereas carers provided a larger picture of their learning journey (often extending over months or years) and the reality of managing procedures in the whole-of-life context. In these findings, data from both perspectives have been combined to produce the grounded theory of an overall learning process.

A. Setting out on the learning journey

Carers who took on the management of technical health procedures needed training for their new role. The most concentrated teaching by health professionals occurred as they set out on this new learning journey. In this stage, we will consider who the learners and teachers were; where teaching took place; the health professionals’ considerations as they began teaching with a new learner; the components of a technical health procedure and methods used to teach them; the time taken for teaching; the emotional experience of carers; and two particular concerns of health professionals (mitigating risk and ensuring carers’ competence).
Learners and teachers of technical health procedures

All the family carers had received teaching about technical health procedures from nurses. These nurses had either general roles (ward staff or a district nurse) or specialist roles (for example, a renal dialysis nurse, diabetes nurse educator or continence nurse). In addition, seven carers had had some teaching from a dietitian. Doctors were mentioned in terms of their oversight of medical care, but only occasionally in relation to directly teaching about procedures: for example, in the management of type 1 diabetes (by paediatricians or endocrinologists for three carers), for some aspects of a jejunostomy tube (by radiologists, for one carer), and in some aspects of tracheostomy management (for one carer).

Health professionals had to identify which family member/s would be involved in managing a procedure and therefore needed to be trained. The opportunity for training depended both on whom professionals asked as well as which family members sought to be involved. Teaching was given individually or to family groups, as appropriate and practical.

Among the family carers who were parents, all the mothers but only some of their partners had had initial training from health professionals, although most fathers nevertheless contributed to care. Instead, mothers commonly passed on the teaching they received. The exception was tracheostomy management, where hospital staff had ensured both parents were trained, consistent with recommended practice that two carers must be competent to manage this procedure at home (American Thoracic Society, 2000). The combination of missing out on professional teaching and lesser involvement in day-to-day care left fathers “play[ing] catch-up” (FC9B). On-teaching other family members also occurred with carers of adults, and as with carers of children, raised issues around the quality of information transfer.

We often have these really wide, extended families, all of whom are very keen to be involved, but you don’t necessarily have the continuity of meeting the same family member at each visit. So it’s that thing between trying to balance their keenness to be involved, and the safety around if they’re not present during the times that you visit, that you can’t necessarily update them, you can’t assess how they’re going. I guess the big extended families, it can mean more people are present but it doesn’t necessarily result in greater care because it’s quite diluted, it’s delivered by so many different parties, all of whom have slightly different skill levels, and other families
might be self-taught by one family member and it doesn’t necessarily translate down the line (HP3A).

Teaching was commonly a shared role and learners could therefore encounter more than one teacher: for example, different members of a nursing team (in hospital or in the community); different teachers in the hospital and home setting (if the teacher’s role was limited to one or the other location) or between tertiary and local care; or different members of a multi-disciplinary team each teaching aspects of the procedure. Teachers had different levels of experience and they might themselves seek support and learn from other staff with greater expertise in a particular procedure.

A specialist teacher, such as a diabetes nurse, offered learners in-depth knowledge and experience. They also provided continuity of care (although this might be broadened to continuity within a team if there was more than one person in the role). A single teacher had the advantage of being able to develop their relationship with the learner, meaning that he or she could build on whatever prior teaching had been provided. A disadvantage was that a particular health professional and carer pairing might simply not be a good match of personalities or teaching-learning styles.

Multiple teachers also had advantages for learners, with the opportunity to learn from different teaching styles and different ways of doing something. However, there was also the potential for confusion or inconsistency between different teachers and good communication between all parties was needed for best outcomes.

[During training], they’re going to come into contact with all of the nurses, and I think that that can be a strength as well, because I think that people have different approaches and I’ve seen people struggle under one nurse working with them, and we’ve done a bit of a swap and suddenly they’ve taken off ... As I said to a patient last week, I said, “So much of the learning is the one-on-one that you do with the nurse. The rest of the learning that you do is based on being in the environment with like-minded people, listening to what the nurse says to them, watching what they do and sharing that discussion amongst yourselves as well. That’s part of the learning as well, ’cos you feed off each. And you might have one nurse say something to the patient they’re training and you think, ‘Gosh, that actually makes better sense than the way the nurse explained it to me.’” Rather than being a closed-off process, I think that’s a real advantage (HP8).

And I think at home too, you’re probably going to have a consistent person [teaching], whereas in hospital, you’re going to have a lot of different people with different ways of doing things and different skills and different knowledge about things, and I think mixed messages are one of our key problems (HP2).
Teaching locations

The location of training for technical health procedures depended both on where the care recipient was at the time (in hospital or at home) and where the teacher was based (in hospital, in the community or someone who could work across both settings). When a procedure began during an admission, initial teaching of carers began in hospital. Health professional input might then end on discharge, or continue at home with the same or different personnel. If an in-patient stay was not required, teaching took place in outpatient or home settings.

Health professionals restricted to the hospital setting might not know what the home was like and whether any adaptations to the procedure or risk management strategies were needed in that environment (although these could be addressed if there was a home visit prior to discharge). Thus hospital-based teaching did not necessarily match the reality of how things had to be managed at home, meaning that the transition from hospital at the time of discharge might be more stressful than if at least some training took place at home.

... what they teach in the hospital doesn’t necessarily apply that well to the community, the realities of the home situation, to equipment ... a lot of it is improvising. You know, people have different resources, they have different home environments (HP3A).

In the first week when we started to do the catheterising – because when [the nurse] sent us home, she sent us with these little sterile pre-packs that had like a solution for cleaning and everything like that and so I wasn’t entirely sure like the jump from that to at home ... I’d learnt how to do it with the packs and then I ran out of the packs and then I was like, “Ok, what now? I need more packs!” And they were like, “Oh no, you can just mix up some Dettol”, and I was like, “Well how do I know which strength?” “Oh just do it what the bottle says,” and I was like, “Ok.” Then once we got moved on past that, we were kind of away from there. That was one point that I was like, I learned it with the packs, I learned it with those things, what am I going to do now?! (FC6).

The hospital setting was less private than the home; one health professional reported this sometimes inhibited learning as “families don’t want other families to know why they’re there” (HP1), although another health professional and some carers commented on the increased opportunities to pick up new ideas.

So there’s definitely a lot of talking [with other carers], especially when you’re in hospital on the ward and there’s not a lot to do, there’s
a lot of talking there and getting information and you do find out different ways and things like that (FC7).

For learners, an institutional setting provided security with professional back-up always available. However, learners also had to bear some or all of the costs of time and travel in coming to a hospital for teaching and, particularly where this involved travel to secondary or tertiary centre, this limited who was able to attend training sessions.

[In an in-patient setting] it’s okay a nurse leaning over and telling someone how to do their sub-cutaneous medication; you walk away and if they’re doing it wrong, you’re there telling her, “This is what you do” but at home, they’ve got no reference point, which is what was behind having this education package that’s given to the family with pictures: this is what to do, this is what to look for ... And they may only need it at the beginning until they’ve become confident, but you know, teaching something in a safe environment is quite different to them doing it at home (FC11).

Home-based training was seen as “the ideal environment to be teaching because you can actually adapt it to the environment” (HP2) and learners were more comfortable in their own space: “I’ve found too that mum – it’s usually mum – is much happier to talk at home because she’s in her own house” (HP4).

Health professionals’ preliminary considerations

For the health professional teachers, there were a number of factors to be taken into account as they began teaching a carer how to manage a new technical health procedure, including their willingness, suitability, capability and readiness to learn; what preparation and prior learning carers had; their learning needs; and cultural considerations. However, while these all featured in the health professional interviews, consideration of these factors seemed to happen largely intuitively in the course of teaching rather than through formal assessment processes.

In determining who to teach, health professionals used verbal and body language clues to assess people’s willingness or reluctance to learn a particular procedure or aspects of it. In addition, they considered people’s suitability: “You sort of have to vet each carer as they come along and then decide whether or not you think they would be appropriate” (HP6). Suitability (or not) reflected risk to the care recipient (such as the “over-confident” person who “might do something quite dangerous”
or to the carer themselves (such as a step-father who might be put “in a compromising position to be doing some cares” (HP6)).

Some initial assumptions might be made about a person’s capability of learning, but this could be better judged as teaching proceeded:

Often the staff will say, “Oh gosh, we’re dreading this patient training, because they’re going to be nightmare” and do you know, sometimes it’s the ones you expect to be a problem will cruise through, and the ones that you think are going to be okay, there’ll be problems with. And sometimes it might be the young, who you perceive to be more capable, who tend to sometimes have more issues, so I just say, “Look, you cannot pass judgement on anything. It’s a new situation every time we have a patient” (HP8).

We’ll probably generally go on a, try someone’s capability initially, see how they go and monitor, in the start, so it’s not like we’re assessing people to prove what they’re capable of. You’re kind of asking them what they’re happy to do and then going from there, and if they feel they didn’t have a good experience with doing that, then we can kind of adjust how much [professional support] we’re providing, and that sort of thing (HP3B).

Health professionals looked for signs a person was ready to learn, such as their asking questions about a procedure and its management; this could provide a lead as to where to begin or build on teaching, rather than inflexibly following a set programme. Even if learners expressed interest, professionals sometimes judged that it was not an opportune time for teaching, such as when a family was trying to cope with a changing clinical situation and a lot of other information and decisions at the same time. Other indications of a lack of readiness for learning included the person’s emotional state and lack of engagement with attempts to demonstrate or teach care.

In addition to waiting for learners to be ready, professionals actively worked to create readiness. Where advance planning was possible, they helped prepare learners though explaining the procedure, providing written information or showing equipment. They might suggest a person considered learning to manage a particular procedure, and reassure them they were capable of learning and would be supported to do so. They also provided opportunities for learners to observe the procedure being done, thus becoming familiarised with what would be involved. Lastly, they tried to optimise the environment for learning (such as providing privacy or time away from the care recipient).
Family members or carers, when we first say to them, “How would you feel about learning to give Billy, Bob, Joe, whoever, a small injection of extra medication as and when they need it?” they’ll often say, “No”, but the patient will then meet a crisis point and then they’ll see that actually, had I learnt to give that injection, I could have responded really quickly to their needs and then called the nurse for more support. So once they see the place and the role and the impact that them learning that skill could have, they’re very willing and happy to learn. They’ll often come back and say, “Actually, I’ve been thinking. Last night, it would have been really great if I could have given that medication. Can you show me?” So it’s all about their readiness. So often we’ll put the idea out there to them: “How would you feel about it?” – and then leave them to think about it, and then they will often come back to us and say, “That is something I want to take on” (HP3A).

Despite a preference for teaching when learners were ready, professionals recognised that in reality, there were times when they had to begin in less-than-ideal circumstances in order to facilitate a person going home (for example, parents might take some time to come to terms with their child being diagnosed with type 1 diabetes, yet needed to begin learning how to manage their child’s treatment almost immediately).

Another factor for health professionals to consider when planning their teaching was the carer’s learning needs and style (“different people learn in different ways” (HP12)), including any past experience, what they needed and wanted to know and cultural needs. Past experience influenced (positively or negatively) a carer’s willingness and confidence to take on further care and prior learning provided a foundation to build on (or was at times problematic).

I guess the other thing we’ll sometimes come across is someone who’s been a caregiver for a previous family member and had that experience [which] will often influence their willingness or their feeling about going into another close, caring relationship ... Sometimes it will really inform what they’re doing and they have a whole lot of competency and confidence around it because that was what they did for dad, that sort of thing. But in some situations it might be that that was a painful experience or something that was really difficult, and to be going into that again, can be high anxiety around it (HP3B).

Sometimes ...[carers with experience have] learnt behaviour that might not actually be necessarily helpful, so trying to steer away from that and also trying to not make them feel bad, because they might have been doing something wrong and you want to change it (HP2).
Organisational policy and teaching resources (such as teaching materials and checklists) provided structure for teaching. In addition, the learner’s lead determined how much detail they wanted to learn: “Do they need to know what this button actually stands for, or do they just need to know that in that circumstance, push it? So some patients don’t want to know how, you know, and others want to know everything” (HP8).

Cultural factors were seen to influence learning needs and preferences too. Some health professionals spoke about understanding and respecting cultural mores when teaching and support with cultural needs was sometimes given by cultural support services (provided within a district health board or by community organisations). A particular concern was ensuring communication and comprehension when the learner’s first language was not English. Visual cues were especially useful where language was a barrier, or an interpreter was sometimes used, particularly for “the things that are really vital, important” (HP6). Professional interpreters were recognised as the ideal, but other family members also fulfilled this role. Those interviewed noted there were limited written materials in languages other than English and an interpreter might also be asked to translate resources. Resources in other languages might be available via the internet, but professionals could not assess their quality if they were not proficient in the language.

**The components of teaching or learning a technical health procedure**

There were several aspects to learning any procedure. Firstly, there was education about the broader health condition which necessitated the procedure. Then there were the practical techniques of the procedure, including hygiene and infection control for both the carer and care recipient. For ongoing management, carers might need to be taught clinical reasoning and decision-making skills. It was also important that they were able to recognise problems and either deal with them or know when and how to seek help. Finally, carers needed to know how to obtain equipment supplies and dispose of waste material safely.

The balance of these learning components varied depending on the procedure. For instance, in teaching type 1 diabetes management, the techniques of doing finger pricks and measuring blood glucose, along with how to inject insulin, could be learnt quite quickly, but understanding how to make decisions about the insulin dose was an
ongoing process. The initial focus of teaching procedures was on developing practical skills with sufficient knowledge to manage safely; other aspects were developed through ongoing teaching and the carer’s own experience.

The teaching processes health professionals described were semi-structured, with things like checklists or a teaching plan providing a guide to ensure everything important was taught, while also having the flexibility to tailor teaching to the individual situation. They used multiple teaching modes as appropriate to convey different skills or information and to engage with people’s learning styles: “Health literacy is a huge area. I tend to use a mixture of ways of presenting material, so I draw pictures and we have the DVD and we have written material and we have lots of practical hands-on demonstration stuff” (HP4). Professionals also gave evidence of individualising their teaching with regard to their own ability to relate and communicate, in relation to the home situation and depending on the likely length of a hospital admission.

It depends on what the procedure is, it depends on how long they’re in hospital for, it depends sometimes where the family live, because we do get a lot of out-of-towners, and sometimes families that are a bit out of town and a bit isolated need possibly a bit more than other families. And it also depends on the parents, their ability to understand the information as well ... So all those factors are taken into consideration (HP1).

One health professional participant stressed the importance of focusing on the learner’s needs and the desired outcome (becoming competent managing the procedure), then being flexible about how the goal was achieved, rather than being process-driven:

... probably one of the traps, I think, that sometimes people can get into, [is] thinking that we have a process and the patient has to slot into that process, rather than the end point is getting the patient to be able to do this; what do we need to do to get them to that point? And so I’m very focussed on that side of it, rather than, day one you do this, day two you do this ... So very much, it should always be about tailoring the training to the individual person and I think that that’s something that is always an area for development. I think some staff ... might say, “They’re just not getting it.” And I will say, “They’re not getting it or we’re not teaching it to them appropriately?” (HP8).
Methods of teaching a technical health procedure

A number of methods were used for teaching technical health procedures, in assorted combinations as relevant for the particular procedure and its learning components. In terms of practical skills, both family carers and health professionals most commonly described some form of explanation and demonstration of the procedure by the teacher, followed by the learner practising under supervision: “So we usually do that thing where you talk to them about it, show them and then you get them to do it as well” (HP1). Procedures could be broken down into a sequence of steps, and carers sometimes began by learning only a part of the process then building on this as confidence and competence were gained.

Carers also absorbed learning by watching practical aspects of a technical health procedure being performed, particularly repeatedly (“I think what helped was he’d seen it done thousands and thousands of times” (HP5)), but doing it oneself was essential for complete learning: “You can research to your heart’s content, you can watch videos, but until you actually try it ... I think the hands-on is the huge part of it” (FC5). Repeated practice reinforced and developed technical skills: “Because it’s something that’s repetitive, you can continue to do it regularly ... and your technique should improve the more you do it” (HP5).

Supervised practice allowed learners to get feedback about their performance and health professionals to observe whether the procedure was being done competently. However, two carers recalled occasions when a procedure had been explained, shown (in one case) but they had not had the opportunity to practise it before taking responsibility for managing it. Two others had felt confident enough to try replacing a nasogastric tube by themselves without supervision after seeing it done by a health professional a number of times.

So then after he’d had his surgery, then they said he would need [bowel] washouts and the poor Sister on the ward had to try and explain washouts to us, being unable to do one on [my son] because he was just post-op, but having to try and talk us through and just go round the ward and gather up what supplies she could. So she did talk to us about it, but they were used to doing washouts that were more like enemas, whereas [my son] needed more what you’d call an irrigation ... So again, the washouts we sort of learnt ourselves. There was good stuff on YouTube from Cincinnati Children’s Hospital (FC18).
So I basically taught myself [to replace a nasogastric tube]. What happened was I used to watch the nurse and you’ve got the little pH testers and things so you can test, and then one afternoon it came out and it was outside of the nurses’ hours and I was not prepared to go to the hospital and I thought, “I’ll give it a go” and I just basically did it and it was fine, so it just went from there. I mean I watched them and they had showed me what they do, so I knew, and it wasn’t actually that hard (FC5).

Carers generally practised directly on their family member, but three had some simulated practice on a mannequin and three had practised injection techniques with a doll or orange initially. Equipment might also be trialled first away from the patient. Another option, for the carers learning to do finger pricks and injections for type 1 diabetes, was to practise on oneself, which also provided some experiential understanding of what it was like to undergo the procedure.

Simulated practice removed the risk and fear of hurting or harming a loved one and was used to develop skills and confidence. It also allowed training in some procedures which could not be practised on a patient (such as cardiopulmonary resuscitation). However, virtual experience might not exactly match reality, and at some point, carers still had to transfer their simulated skills to the patient.

... for the diabetes side of it, practising injecting oranges and stuff like that, it came to the point that I thought, “Well to get [my son] home, I’m just going to have to do this, you know. [Became tearful.] ... So it’s just getting over that first, that barrier, really, and that first injection (FC21B).

We do have an artificial arm. It’s not used terribly much ... I think it tends to be that under guidance, they tend to just get in and do it with the patient because you don’t get that same sense of doing [on the model as on a person] (HP8).

Alongside practical demonstration, about half the carers mentioned receiving printed material (written and pictorial) about the procedure(s) they learnt. In addition or instead, some carers took their own notes or followed the instructions that came with equipment. Some material focused on how to perform a procedure, setting out the steps which could be followed as a prompt. Other resources included broader information about a condition and its management or advice about potential problems and what to do about them; these were useful to refer back to if the situation arose.

The printed material carers had ranged from one page to a 184 page A4 book (the latter provided for people managing type 1 diabetes). Most written material was
generic to a procedure. However, one couple had received lengthy written protocols individualised to their child’s needs for a complex intravenous drug regime when seizures occurred. Apart from one person who was happy to just learn visually, having written material to refer back to was appreciated and three carers who had not received anything mentioned they would have liked some.

Health professionals also discussed their use of written material as prompts and for future reference. These included generic information sheets produced by a health service for a particular procedure, education leaflets produced by a company making products for a technical health procedure, and specific instructions and a management plan for an individual patient and her carer. For busy health professionals, having sufficient time to create their own resources was an issue, while existing material from other sources might need to be adapted:

You have to be very conscious that there are some clinical practices that might be a little bit different from hospital to hospital based on different doctors’ ideas about things. So that’s kind of what you need to highlight – key differences that we might be teaching and why we might be doing that (HP2).

None of the carers referred to the use of audiovisual material in their teaching, but two health professionals mentioned this mode. One had “a DVD that we give to the patients pre-operatively” (HP7) and the other a DVD that could be used when teaching families as well as providing information for schools.

For teaching clinical assessment and decision-making or problem-solving, professionals might use “What if ...?” scenarios or coach the person to figure out what to do:

Or sometimes giving people a scenario, like saying, “If Bob starts to look really distressed or agitated, what sort of medication do you think you could give? Or if the catheter blocks tonight, what sort of things do you think you could do?” (HP3A).

What we do also is get them to keep a log book, so all the [insulin] doses are written down and all the blood sugars. So we’re looking at trends when they report them back to us and we’re saying to them, “Well I’m doing this because yesterday da-da-da” or, “You’re telling me that today she’s got ballet from three ’til five [pm], so we might just think about changing the insulin around that.” And then towards the end of that [first] two weeks, I’ll actually say to them, “So what do you think? What dose do you think?” And that way they’re coming into doing it more (HP4).
Carers drew on their own background learning and experience too. Some who had a health professional background could utilise previous specific training or apply transferable skills (“I’d done them [injections] when I was nursing so it didn’t really faze me too much” (FC2)). Other carers referred to their “common sense” (FC2,4,5) and to past mastery of one procedure contributing to confidence in learning another skill: “Because I suctioned her regularly, deep suction her, getting it [nasogastric tube] round that piece in her nose was easy” (FC14). On the other hand, even extensive personal experience did not necessarily make it easy to manage a procedure for another family member, as reflected by this mother who herself had type 1 diabetes, then realised her son did too: “I struggled with that admission, I really struggled. And maybe it’s because I knew what was involved and I found it very hard. Here was me injecting myself, but I couldn’t inject my son” (FC21A).

**Teaching time**

Health professionals utilised both focused and opportunistic teaching time. Ideally, focused time was planned around the learner’s convenience and readiness, but the realities of other demands on professional time meant this was not always the case. In addition, professionals seized teachable moments during patient care episodes or when family members were visiting.

Initial teaching ranged from a single half hour session, to input over a few days to a week, to daily sessions for several weeks or months. The required duration was not fixed (although health professionals could indicate how long various procedures “generally” took to teach), but depended on two factors: ensuring the carer was competent to manage a procedure safely and that they were confident to manage alone.

The time required to become competent differed according to the complexity of a procedure (more steps, the need for broader understanding about a health condition or the need to vary a procedure in response to clinical assessment all increasing the teaching time). Further, competence was related to risk and safety. Thus a carer managing a low-risk procedure might not be fully competent at the time of hospital discharge, but could continue to learn with professional support at home. On the other hand, carers managing high-risk procedures had to demonstrate a greater level of competence before ‘going solo.’
If someone’s on haemodialysis, they’ve got to learn to set a machine up, put needles in their arm, have confidence with that; they've got to manage alarms that happen. There’s a lot more from a safety perspective and just a technical perspective to learn. So they also have to learn about fluid balance control and everything, waste management and all that sort of stuff. I think the shortest time that someone’s trained would be seven to eight weeks, so that’s 24 treatments. The longest person might take six to nine months ... Somebody learning to do peritoneal dialysis, where there’s a tube in the tummy and the system is just running a bag of fluid, connecting up, a bag of fluid in, leave it in for four hours and then drain it out, the actual procedure itself taking about 30 to 45 minutes, four times a day ... Repetition. It’s the same. Read the prompt sheet. It’s the same procedure all the time. They also need to learn things about trouble-shooting, dietary management, fluid control, medications, but all of that is largely learnt within five days ... If a nurse is not comfortable and does not think the patient can do it safely, then they’re brought back for another week. So most patients only need one week, but if someone needed two, they’d get two (HP8).

Health professionals also wanted learners to feel confident with what they were being asked to do. They attempted to build confidence by giving learners time to observe a procedure and ask questions beforehand; affirming their ability to learn; affirming achievement of tasks; and assuring them of ongoing support as required. Confidence might lag behind competence and necessitate continuing professional support. The intensity of ongoing professional teaching and support reduced as learners’ competence and confidence developed.

[We] keep them in until the family feels confident about going home and often we can have finished our education and say, “Yes, they know what they’re doing but they’re not ready for discharge” and we’re quite happy to hang onto them; don’t want to rush people out the door (HP4).

The focus of teaching by health professionals was on the initial, concentrated period of training. Beyond this, they might or might not be involved in ongoing teaching, either proactively, reactively when requested or opportunistically (such as when seeing a person at an outpatient clinic for another reason).

The emotional experience of carers in the initial learning process

For family carers, their initial (and ongoing) training was not simply a matter of cognitive understanding and practical techniques; it was also an emotional experience. Procedures were not discrete entities but part of the overall health or disability context.
which necessitated them. Hence carers were coming to terms with changes and the implications for the future. Not surprisingly, therefore, this could be a stressful time. Trying to learn new information at this time could be difficult and carers themselves needed support.

... in that really new, raw place, I think it’s really hard to take on board new things. I think you can only take on little bits at a time, and it’s kind of like layers – you gradually build up, slowly. They [clinicians] probably thought I was a bit thick at the beginning, because sometimes they would tell me things and it wouldn’t sink in, I wouldn’t understand, or it was too painful to take in ... I guess I wanted professional people to be understanding and supportive of me when I was a new parent, very understanding and kind, because it was really hard, and I needed somebody who was able to listen and hear me, and so I wanted people to be nice and kind and gentle with me. And I guess in a way I was kind of looking for some caregiving from them in a way, there was a little bit of that, ’cos I needed it. So as well as just the information, medical information or whatever, you’re wanting something – yeah, some sort of support, that’s very important in the early days, ’cos it’s all so, you’re so raw and blah (FC17).

Carers commonly described themselves as being “nervous” or “fearful” initially about performing procedures and needing health professionals “to reassure me that what I was doing was correct” (FC14). Some had to cope with their own squeamishness; learning to do this happened through “necessity” (FC16) and in the context of relationships: “I don’t think there were any other options and when it’s your own child, it’s a bit different. Like changing their nappies and stuff. Other people’s kids, it’s like, ‘Ugh, how can you do that?’... but you just do, because it’s your kid” (FC22). A mother gave this description of inserting a nasogastric tube at home the first few times:

It was awful. The first time it was frightening. I can remember setting everything up, and it took me a good half hour just to set everything, something you do in two minutes once you’re used to it, a couple of minutes, but I’d have to psych myself up, and I’d just absolutely dread doing it ... I would psych myself up, because it was so frightening and I was so alone, even though they’re [district nurses] there at a drop of a hat if you want them, and I’ve got a really good team up here in [city] (FC19).

Health professionals recognised carers could be in a state of shock to begin with and “the distress stops them from learning well” (HP2). This was generally worse for those who were unprepared, but even with preparation, the reality could still be a
surprise. Ideally, teaching would be timed to match the learner’s emotional readiness, but this was not always possible. Repetition of teaching, affirmation of the learner’s competence and additional support for carers in the initial phase (including at the point of transition from hospital to home) were important.

Generally you can sort of feel, sort of see that they’re not, things are just too much, and then you just say to them, “I think that’s enough information” and then you just come back and revisit it. Or sometimes you say, “Is anyone else coming to visit you today? Could I do it then? Or when does she normally have a sleep?” You just work out with them when to come back. But in reality, you do that and then you get tied up with something and you don’t always get back and that can be a bit of a problem as well (HP1).

Carers’ anxiety about doing something painful presented a particular barrier for health professionals’ teaching. At the extreme, carers might refuse completely and “they’ll outright come and say, ‘If you’re going to ask me whether I’ll administer this, the answer is ‘No’” (HP3A). Alternatively, they might agree to learn but be “hard to teach because their emotions get in the way of seeing the practicalities of what they need to learn” (HP2). Here the professional’s focus was primarily on meeting the patient needs (by ensuring carers managed a technical health procedure on the patient’s behalf). Other health professional participants presented a more holistic picture of considering both patient and carer needs.

Professionals were able to draw on their prior experience with a procedure and their knowledge of the learning process to put unpleasant aspects in perspective. They used a variety of strategies to help carers overcome their distress, including emphasising the necessity and benefits of the procedures (“You just have to convince them it’s the right thing to do” (HP2)), offering reassurance (verbally and by demonstration) that the procedure would not in fact be harmful and that the carer would be able to learn and manage, and finding ways to minimise any pain.

At some point, a learner had to actually do the procedure. As discussed earlier, this was generally preceded by the professional demonstrating and explaining it, and looking for signs of the learner’s readiness to have a go. In teaching, being “very matter-of-fact” (HP4) focused attention on the steps of the procedure and thereby reframed it as a non-emotive task. Getting a carer to do something provided them with an actual rather than imagined experience of reality and successful repetition desensitised an anxious person: “the more they do it, the better it is” (HP2).
I think once they’ve actually done the first one, that’s a huge psychological barrier over with, ’cos the needle isn’t 10 feet long and two inches thick. Once they’ve done it, it’s, “Oh!” – it’s almost an anti-climax. And I want them to experience that as soon as possible so they’re not sitting there fearing what it is (HP4).

For carers who were very stressed, such that “it’s just so overwhelming to them they can’t learn stuff” (HP2), an option was to begin teaching away from the clinical situation or to use a mannequin for practice, thus enabling the carer to focus on the task rather than their own or the patient’s emotional reaction to it. Occasionally, specialist psychological help was needed (for someone with a needle phobia, for example).

Ultimately, some potential carers remained resistant or unable to manage a technical health procedure. In this case, an alternative had to be found – another family member, possibly continuing professional care in the community or a move to residential care.

*Health professionals’ concerns in teaching technical health procedures: mitigating risk and ensuring carer competence*

For health professionals, assessment of risk and ensuring patient safety were integral to their teaching. Allied to this was assessing carers’ competence in managing a procedure. Thus while one health professional asserted, “I don’t think there’s any limit to what people can learn if they’re wanting to learn” (HP3A), a later comment by the same participant recognised that this theoretical view was curbed in practice by safety concerns: “… we assess their competence in doing it, and if we judge someone as not being safe to do it, we probably wouldn’t go ahead with teaching it” (HP3A).

Technical health procedures varied in their risk depending on how vital the procedure was for sustaining life; how complex the technique and equipment were (thereby increasing the possibility of making a mistake); and the potential for harm if things were managed incorrectly. Carer personality might also contribute to risk, with the over-confident person perhaps “a bit blazé” (HP5) about sticking to the rules.

The degree of risk influenced the boundary of what professionals permitted carers to manage. Thus procedures, or aspects of procedures, which were perceived as high risk were generally retained in professional control. For example, although parents could be taught to administer intravenous antibiotics at home (including mixing and injecting the antibiotic and flushing the line), “We don’t normally let the parents do the
central line dressings ... because the potential for infection [is] huge. So that’s normal practice, that’s part of our policy that we [nurses] do the dressings” (HP6). However, an example was then given of a parent who had transgressed this professionally-delineated boundary and gone ahead and changed a dressing herself. Moreover, boundaries were not absolute, but might be shifted to facilitate home care in situations where the family were willing and professionals judged that a ‘safe enough’ environment could be created. Acceptable levels of risk might therefore differ between professionally-controlled settings and home care, and giving families control of technical health procedures required trust between the two parties. The two examples below illustrate, from both the carers’ and health professionals’ perspectives, the negotiation of boundaries and consideration of risk.

So we decided in our wisdom that we would take [our daughter] home to die and we wanted to be a family just for a while and she was spending so much time down there [in hospital], and once they put the IV in, they said, “Look, this is it; you can’t go home [because of the complexity and risk of the intravenous drug regime].” We watched and watched for weeks and we sort of saw how it all worked and we said to them one day, “We want you to teach us how to do that. We want to take her home.” They initially said, “No, no, no, no, you can’t do that.” We sort of looked and said, “Well why not? Come up with a really good reason why not.” So the oncology nurse, bless her heart, taught us how to run, how to change the needles and how to run a syringe driver pump ... So they taught us how to do it and they wrote up all these wonderful protocols and things and instructions and popped it in a folder and the day came when she was well enough and we packed our little bags ... [and] off we went. We got home (FC20A).

We still mitigated it [risk] as much as we could, and we told them what the risks were and they had to take the responsibility for that in themselves. From our perspective ... we weren’t doing this for us, we were doing it for them [because they wanted to be at home] ... I mean, there is a risk the tracheostomy could come out, the ventilator could die, all sorts of stuff like that, but we put in risk strategies around, to deal with those things, and we tried to think of absolutely everything, so we’ve dealt with that as much as we could, but I think if we’d over-risked it, then they wouldn’t have got home. So you just have to say, you know, “These are the risks. Are you willing to take them?” We haven’t made them sign anything or anything like that, but we just said, “You’re taking on a big task here; do you wish to continue?” and then we’ve said we’d support them (HP5).

Professionals used a number of strategies to mitigate risks. Some procedures might have boundaries set by organisational policy, as with the example of intravenous
antibiotics above; in other cases, however, it seemed to be a matter of professional judgement as to who and what could be taught and what should remain under professional control. Adequately training carers and ensuring their competence was clearly crucial to reducing risks. Some equipment came with in-built safety features (such as a machine which would not work and would set off an alarm if it was incorrectly set up) or might be able to be programmed to a fixed setting (rather than the carer needing to learn when and how to adjust it). Written information could provide a reminder of how to do a procedure correctly and guidance about managing problems, including when and where to get help. Professionals continued to offer advice and support to carers at home, either proactively or as requested. In situations where professionals considered patient safety was at risk through poor family care, they would attempt to improve the care or, ultimately, remove the patient to a safer environment. When they recognised carers were at risk, they attempted to offer more support or respite. Risk was also a factor in the amount of teaching carers received and the level of competence expected before they are allowed to manage on their own. More was expected for critical procedures, including recognising and dealing with problems.

Interviewer: I know everything will be different, but how much teaching do people get before they go home?
Health professional: Yeah, again variable, and depending on how much that thing is vital, I suppose, and what the implications if it goes wrong are. So if you’ve got a kid that’s relying on something, it’s the make or break of them, that’s something we are really serious on. But if it’s something [less critical] ... I suppose you can relax your assessment of how much knowledge they have because you know that whatever they do – I mean, this is the ideal situation, but it’s not going to be too harmful if that happens. Versus something that could actually be quite detrimental to their wellbeing (HP2).

Health professionals assessed two aspects of carer’s competence with regard to a technical health procedure: practical skills and knowledge. Competence with practical skills was demonstrated by consistently proficient performance. Knowledge was tested by techniques such as a multi-choice quiz, having learners explain back what to do or giving them scenarios to respond to. These might highlight gaps which the teacher needed to address. For some procedures, capability was assessed and documented against a standardised checklist; for others, the teacher would document what they had taught and the evidence of competence. Documentation provided information for other
health professionals involved in care and teaching, as well as evidence that professional responsibilities had been discharged.

Ideally competence, as assessed by the professional, was matched by the learner’s own sense of competence and confidence to manage the procedure. However, the two were not necessarily aligned at the same time. Sometimes a professional considered a carer to be competent before the carer felt comfortable with what they are doing (necessitating continuing support), while conversely, a carer might be falsely confident when “they don’t know what they don’t know, but they think they know it!” (HP2) which could expose the person they cared for to a risk of harm.

Interviewer: And how do you assess that point at which the person is ready to fly solo and go home? ...
Health professional: ... [We have a] checklist. When you’re confident that everything they need to know has been covered, so they can repeat back some of that stuff, they can demonstrate they can do it (and that’s got to be consistently – they can’t just demonstrate that they can do ‘a’ bag exchange; they have to be able to do it over a repeated amount of times), and I think when they express that they’re comfortable (HP8).

I think they would have let us stay and keep watching us do it until we said, “Yip, we’re comfortable.” But after the second time I did it I felt comfortable, I knew how it should feel and that kind of stuff (FC6).

Carers described health professionals watching to ensure they were doing things correctly, and one couple had been provided with a certificate on completion of their learning to manage an intravenous drug protocol. However, as noted earlier, some carers had started a procedure without any formal assessment of their competence:

So I basically taught myself [to pass a nasogastric tube]...They never actually ever asked me to do one in front of them. They were just like, “Oh you’re doing it, you’re fine”, so no-one actually ever followed up to make sure it was being done correctly which I think was a little bit poor, but that’s just what happened, but I guess they felt I was confident enough to do it in the first place, that I was doing it correctly. No, they just kind of left me to it (FC5).
B. Continuing the learning journey: Novice carers

Having described the foundational training of carers managing technical health procedures, we will now explore the next stage of their learning journey. As noted above, the first phase of teaching was focussed on ensuring carers were sufficiently competent to take responsibility for a technical health procedure at home. However, their learning was not completed at this point. This section outlines the features of the next learning phase as carers took on primary responsibility for managing technical health procedures; the learners here are referred to as ‘novice carers.’ The subsequent section will examine the development of expertise though ongoing learning.

Novice carers were continuing to develop their skills in managing the procedure(s) they had been taught. In particular, some had to develop strategies to cope with repeatedly doing procedures which were unpleasant or painful for the recipient. In the home environment, carers now took responsibility and control of procedures. Alongside their technical learning, novice carers were also adapting to life which incorporated these procedures.

**Continuing learning and refinement of the procedure**

Novice carers continued to reinforce and extend their learning, including how to manage problems. In general, they closely followed the instructions they had been given. Indeed, being left with too much flexibility at this time could be disconcerting and changing from hospital conventions to home methods was confusing at times. While mostly sticking to the rules, carers also began to individualise standard procedures for their specific situation and at the same time, health professionals might be advising some adjustments in response to a particular patient’s needs. The carer below described both her initial exactitude with doing the right thing as well as figuring out how to individualise part of the blood glucose testing procedure on her son:

So to start with, it is quite black-and-white: “If he’s [got a blood sugar] between this and this do this” – but for us at the moment during the day, if he has his blood sugars are quite high, he can have a correction of between three and five units so I make the call on that now, but to start with they wouldn’t have let us ... I guess when we left hospital we were so anal about it! I actually had a chart, I remember now, you’ve just reminded me. We had a chart: “At this time give him this and this,” and I had a whole day and it would also
say, “Do your blood tests five times, feed him at this time” and so to start with, we really stuck with this strict structure (FC8).

[Demonstrating on herself a lancing device for drawing blood for glucose testing:] With [our son], we would do that and then no blood would come out and you’d know he’d had a pinprick and I could just feel that pinprick then, and then you’re trying to get the blood out. So that would be worse for him that you just couldn’t get the blood out [and have to repeat the procedure]. So it took quite a while to figure out, well he needs it to be on a three not a two or something to cause it to break through the skin, so all that kind of thing. So that was actually hard (FC8).

The above quote is also an illustration of problem-solving. Carers at this stage of learning were thrown by unexpected events (even if they had been taught about them) or were aware when something was wrong, but did not necessarily know what to do about it themselves. Hence they appreciated having ready access to professional support and advice when needed. Further learning occurred through the problem-solving process and could be applied again when a similar situation recurred.

A low blood sugar treatment is hard to [teach initially] – like people can parrot it off, but a couple of weeks ago I had an eight year old diagnosed and she had a low at school and mum rang me in an absolute panic, and I said to her, “Just remember what we talked about. What you do now is – ” And once I started saying it to her, she, “Oh that’s right, okay, okay, I can do this.” You know, poor lady, she was just overwhelmed by it all and the child was pale and sweaty and droopy in front of her and she couldn’t quite remember it. So she’ll know now (HP4).

Related to managing problems was making decisions about discretionary activities. Thus while a carer described giving injections as “pretty easy ... no problem,” he added, “The hardest thing would be to know when to give it ... and how often ... They had given me rough time periods to go by ... [and] you just had to make judgement, there was no hard and fast rules, but it was hard for me to make that judgement” (FC3). This illustrates that fully learning a technical health procedure went beyond the technique per se to these broader areas of problem-solving and decision-making.

For some carers and procedures, regular professional teaching continued beyond the initial concentrated teaching phase (for example, for families with children with type 1 diabetes). However, for most, professional input was now ad hoc when requested by the carer. In addition, carers made use of other sources of learning, particularly the internet and other carers.
Some carers used the internet to check and better understand the information and advice they had received from health professionals, to seek further information and alternatives, and to problem-solve. The internet provided written material, videos (such as being able to see a technical health procedure performed) and the ability to connect with other carers for mutual sharing of information, advice and support. Amidst this were examples of carers sifting internet material and being aware it was not all correct or applicable to their particular situation.

Dissatisfaction with the information provided by health professionals (or the fact none was given) was a particular driver for carers to seek it elsewhere while also expressing a wish for greater professional assistance:

Interviewer: And how about medical information or information from the professional system or –

Carer: Well, our paediatrician gave us some really old, outdated information that was of no use whatsoever, and actually I gave him some of the information we had found and he was quite interested in that! And most of the people we’ve talked to in the hospital haven’t even heard of the sources that we’re using for our information which is kind of frustrating, ‘cos you look to your medical professionals to provide you with information rather than me providing them with stuff – that’s not my job, it’s yours! (FC22).

Health professionals were conscious of families using the internet for information (as well as being cognisant not everyone has access to it) and expressed some concern about the mixed quality of material. Three spoke of sometimes referring people to “reputable” websites, but “We have to do a bit of a disclaimer, saying, ‘This is a good website, however, this is these people’s ideas, not necessarily, doesn’t represent exactly what we think.’ Because we have no control over what else gets put on that [website]” (HP2). Conversely another would “warn people against the websites that offer cures, because ... it’s really unlikely. So we really encourage them to talk about that, if they do find stuff on the internet, and some of our families will come with things that they’ve found and we will talk about it” (HP4). She emphasised her own teaching was underpinned by evidence-based guidelines.

In addition to learning from other carers through the internet, carers often connected with one another in person through carer support groups and conversations in hospital or at clinics or therapy groups. Some health professionals suggested ways carers could network with others and carers also made their own linkages.
The most useful learning from other carers seemed to be advice about “practical management” (FC18) in the context of daily life (like how to transport a feeding pump when out and about with a child), in contrast with the more technical advice health professionals supplied: “She [nurse educator] is very, you get very good scientific information and stuff, but what you get from the other parents is the day-to-day stuff” (FC8). Carers also learnt that others with the ‘same’ condition were in fact different, which broadened understanding of a condition and its variations.

Observing and hearing the experiences of those who have ‘been there, done that’ could provide hope as to “how you cope, how you get through things” (FC7) and comparison with others could also lead to re-evaluation of one’s own experience: “You see a lot of people who are a lot, lot worse off and stuff like that when you sometimes think, ‘God, it’s pretty rough’ but really, he’s pretty lucky” (FC7).

Finally, it should be noted that not all the carers wanted to be part of support groups or found them more or less helpful at different times.

Learning to cope with causing discomfort to a family member

Carers learning to manage a technical health procedure were often initially anxious about doing something wrong or hurting their family member. As their skills developed, they became more confident about doing things correctly. However, for some, the stress of causing discomfort to a family member continued – it was in the nature of some procedures that they would always be unpleasant or painful, yet had to be repeated regularly. Strategies carers used for coping with the ongoing need to inflict discomfort were distancing their emotions, reframing to focus on the benefits of the procedure, humour, and seeking alternatives.

‘Distancing emotions’ meant the carer switched off, at least temporarily, their emotional reaction to the pain being experienced by a loved one, in order to focus on doing the procedure correctly. Afterwards, they became aware again of their own affective response or the care recipient’s emotional needs, although one carer described becoming “bomb-proof ... practically scare-proof, which is not actually a very comfortable place to be; it’s like we’ve gone too far” (FC20A). Health professionals at times encouraged this ‘clinical’ response and the downplaying of emotions: “They have to know that I am confident with knowing, with no emotion doing it, or maybe scared or whatever it is [before I’d be ready for discharge home]” (FC12).
I think if you tend to worry about the child’s feelings too much – that sounds quite bad – but you need to focus on what you’re doing, not how the child’s reacting, because if you get emotionally caught up, which I have had a few times, it makes it so much harder to put the [nasogastric] tube down because you lose focus. So you’ve basically got to go, “Right, we’ll do this, let’s do it,” ignore what the child is doing and just focus on doing it correctly and then you can calm the child after that (FC5).

[My son] would fuss, fuss, fuss, fuss, fuss. So in the end I thought, “This just doesn’t work. We have to be staunch about this [giving insulin injections]” ... it was a mindset change, I think, and it’s still like, “Oh God, I hate having to inject my kid all the time” but no, I’m very matter of fact about it now, it is what it is. And every day I think, “Oh, his poor little tummy!” (FC8).

A second strategy for coping with unpleasant procedures was reframing how they were viewed. Rather than focusing on inflicting pain, carers emphasised the benefits of what they were doing. They also panned out to view the painful times in the overall context of the recipient’s life, thus reducing their apparent magnitude.

Carer: No, that was hard, because I knew that the last thing you want to do is hurt –
Interviewer: Hurt your child, yeah.
Carer: Then of course I thought, “Well I’m not hurting him; it’s making him live.”
Interviewer: So it’s seeing beyond –
Carer: Yeah, the acceptance of the fact that for him to survive this, I have to do this for him. He can’t do it himself. So it’s just getting over that first, that barrier, really, and that first injection (FC21B).

And the thing is, she’s actually really happy... So I think, yeah, I’ve learnt that there are moments of pain in her life, but by and large, she’s a happy girl. She’s not in pain 24/7. It’s really only when we’re doing the cares of the MicKey button and that sort of stuff (FC14).

The next quote reflects the use of humour to mask causing some pain. In this case, the adult recipient was also able to understand the benefits of what was being done, and consent to it. Inflicting discomfort in this situation might be easier than for parents doing something unpleasant to a young child who cannot appreciate it is in their best interests.

Interviewer: Ok, so you’re putting the needle through skin.
Carer: Through skin, then through the diaphragm [of the portacath].
Interviewer: So is it painful for the person?
Carer: Um, she says sometimes it hurt a bit, but it’s not rolling round the floor.

Interviewer: Right, right. So how about that, were you worried about causing pain or anything like that?

Carer: “Don’t worry, this’ll never hurt,” you know! [joking/laughter] “It won’t hurt a bit!” No, she’s a brave person.

Interviewer: And you were obviously taking good care, I’m sure.

Carer: No, she would have said if it hurt. But she never really, like sometimes the B12 ones hurt a bit, but she saw the advantage of it (FC4).

Finally, the ongoing stress of causing pain led some carers to seek alternatives, including finding ways to avoid the situation in the first place (for example, carefully taping a nasogastric tube so it would not come out and need replacing), seeking another solution (such as replacing a nasogastric tube with a gastrostomy), or refusing to manage this aspect of a procedure (necessitating alternate care arrangements).

**Taking responsibility and control of technical health procedures**

As carers transitioned from a period of intense initial training with professional support to managing without help immediately on hand, they became more aware of the responsibility they had taken on:

They [nurses] were always there [in hospital], so that was weird too because when you got home, they weren’t there and suddenly you were by yourself, although ... we could ring [a nurse educator] any time of the day or night (FC8).

I think sometimes patients don’t know – it’s different doing something when someone’s sitting there watching you and supporting you and telling you you’re doing a great job and how wonderful you are, and then you get home and you’re all on your own, and suddenly that’s a very different world, and then 30 boxes arrive at your house and you think, “Where the hell am I going to store them?” That’s the reality of what you’re doing, and that’s the reality that you have to deal with (HP8).

As carers took primary responsibility for procedures at home, there was also a shift in control. In a hospital setting, health professionals have greater power over how things are done, but the home is the family’s domain and professionals enter as guests rather than of right. As carers “get into doing their own things their own way at home” (HP1), some chose to relax some rules – or conversely, be stricter:
... the asepsis or the sterile or the clean conditions is possibly not as good [at home], maybe, or sometimes it goes the other way as well – you know, we generally recommend things like NG tubes and all that don’t need to be sterilised after six months [of age] and feeding tubes and things like that, but parents will go home and they’ll keep doing that (HP1).

The transfer of responsibility to carers was both an expectation of health professionals’ teaching and also somewhat problematic when it raised the issue of risk again. Thus health professionals had to balance respect for a carer’s control over their home life with a professional obligation to intervene if they were aware patient safety was compromised. At the same time, a carer’s control over their home life limited professional responsibility.

Obviously if you’ve got a knowledge of something that’s unsafe you need to address it, and that’s our professional responsibility... But I suppose as long as [the nurse has] actually talked about things and addressed it to the best of her ability, the responsibility still goes back to the parents. And if something happened, if we’ve documented that we’ve done the teaching and that they’ve acknowledged that they understand this and whatever, then it has to stop somewhere, because we can’t be responsible for everything that’s happening. But we just need to make sure that we’re teaching and giving the right advice, I suppose, and document it, that they understand that (HP2).

Adapting to life with technical health procedures

Adapting to life with technical health procedures involved developing routines and deciding on new family rules. Alongside organisation and planning, carers also found ways to be flexible when needed.

For aspects of procedures which had some regularity, routines provided a way to organise and fit them into daily life. (In addition, any unpredictable events had to be responded to as required.) Carers became adept at adjusting routines to fit in with whatever else was happening and to doing procedures when out and about. Having official sanction to be flexible was helpful:

Her urologist, he definitely, he doesn’t encourage you to be rigid [about when to do intermittent catheterisation] and that’s how it has to be, or anything like that. He says it has to fit into your life as well, so sometimes you’re going to have to be flexible – sometimes you have to do it a little early, sometimes you have to do it a little late, don’t stress out about it, and I think being told that makes it a lot easier for
us, so you’re not freaking out all the time, trying to get it done at the right time and stuff (FC6).

However, there were also constraints on how much flexibility carers had depending on the clinical necessity of the procedure and how much this was tied to specific times: “Actually one thing that’s interesting that has changed things a lot for us, we can never sleep in as long as we like now. Never. That’s been a huge change” (FC8).

Other constraining factors were the portability of equipment and individual practicalities (such as a small child who could be lain down on the back seat of the car for a procedure versus an older one who could not). Hence daily life was also adapted to fit the procedures. Adapting was easier within the home, which could be modified to suit, than in the community or even in hospital, where environmental barriers could become more apparent.

A further aspect of adapting was developing ‘house rules’ to manage procedures within family and community life. For instance, one mother recalled going to a restaurant for a family dinner for the first time after her son had been diagnosed with type 1 diabetes – should the insulin injection be done at the table or in the bathroom? “So we had this big discussion at the restaurant ... there weren’t any rules so we had to sort of figure out what is okay. And other people I know would never do that [at the table, as we decided], so it’s just about what do we think is okay?” (FC8).

Another expression of carers’ organisational expertise was arranging and fitting in appointments, obtaining, storing and disposing of equipment supplies and even organising information for professionals (such as a summarised medical history or instructions about the individual’s needs). Like good scouts, carers were well-prepared for contingencies: “That’s the other thing that you always do have to remember, is whenever we leave the house with [our daughter], she has a bag that’s always ready and set up with what she needs” (FC9A).
C. Continuing the learning journey: Becoming and being an expert carer

In time, as learners became technically competent with managing particular procedures and developed their ability to adapt and problem-solve, they could become expert carers. The mother below contrasted the stress and uncertainty she felt during the early period of taking on technical health care with the competence and confidence she had gained through experience:

[At the start] it’s difficult, but it gets better, it gets easier. Initially it’s so overwhelming and you’ve got no idea, but with time comes experience and with experience comes knowledge and then you don’t have to second-guess everything and then you can just do it and know that what you’re doing is okay. There’s no, not necessarily right or wrong, but as you get to know your child, what works for them, and then it becomes really easy (FC14).

Expertise encompassed technical proficiency in performing a procedure as well as understanding how to manage it and deal with any problems within the wider context of the recipient’s health condition. Carers’ expertise was highly specific to the person they cared for and they recognised it was not necessarily directly transferable to another person’s situation (though some had shared their experience and knowledge to try and help other family carers). Expert carers were also aware of their limitations and their need at times for further professional advice or support. All the time, the breadth of their holistic knowledge about the care recipient could outstrip the narrower focus which might come from professional specialisation: “I think a lot of parents of medically complex children, you’re the one person who really holds everything ... we have quite often felt that we are the ones holding the whole thing together” (FC18).

Notably, not all novice carers will become experts – a certain amount of repetition and experience with a particular procedure were necessary to progress to expertise. Without the opportunity to regularly practise a skill, initial teaching might be forgotten and expertise could also be lost when a particular skill was no longer required.

The time taken to develop expertise varied depending on the frequency of performance (more quickly with, say, something done four times per day versus once a week), the complexity of the procedure (faster with a procedure with few steps or potential modifications) and individual personality factors like confidence. As well as technical proficiency with the ‘standard’ procedure, carers needed to experience and
learn to manage variations and problems if they were to become expert. A primary
carer who performed a procedure regularly and made most of the decisions about it
developed expertise and confidence more quickly than secondary carers, although in
time, other carers could develop equal expertise. This was particularly reflected by a
comparison between mothers’ and fathers’ skills, as this mother explains:

So for a long time I felt the burden was all mine. But that’s changed
over time and it’s no longer an issue, so it is an equal, equally joint
thing ... I was very much the primary carer and even though I know
my husband is very competent, I knew he didn’t know as much as me
so if I left [our son] with him, sometimes he’d ring and check: “Oh
his number’s this, am I doing the right thing before we give him
insulin or whatever, is that right?” So for a long time I did that, but
that’s no longer the case so now it’s equally shared (FC8).

Health professionals identified two other factors associated with the move to
expertise: carers having a sense of being in control of managing the procedure and
recognising that their care was to the same standard as a professional’s.

I think it’s about that sense of control that you suddenly get. So
feeling in control ... You’ve been given the task of doing it and you’re
going through the motions of doing it [initially], whereas now, I’m in
control of this; taken it on board; I own it (HP8).

At the beginning she was really anxious that she was doing it [an
injection] right; could she do any harm? And then she said, “I keep
bruising him” but I said, “Actually, even nurses would be bruising
him.” About three weeks later she’s comfortable doing it and she’s
really confident doing it (HP11).

Health professionals were also cognisant that not all carers became experts. For
some, managing a technical health procedure was a short-term role and such carers had
insufficient opportunity to fully develop their skills; some chose not to take
responsibility for higher levels of management, preferring to leave this to health
professionals; and some accepted a certain level of care as sufficient rather than striving
for further competency. The last situation might be acceptable to professionals in the
case of patient self-management and autonomy, but where a carer was managing a
procedure on behalf of a patient, there was a fine line between acceptable care and that
which was perceived as neglectful and requiring professional intervention, as contrasted
in the two quotes below.

I think some people are never going to be experts. I think there’s a lot
of patients doing this themselves who ‘get by’, who know what they
need to know to be able to survive and do okay ... [They don’t follow all the medical advice they’re given.] And they’ll say, “But I haven’t died because I haven’t had blood tests done. I haven’t died. And I’m doing my dialysis when it suits me and I can do everything I want to do.” You know, they don’t need to listen to a nurse who says, “Well you might drop dead one day because your potassium will be so high.” “Well fine.” You know, they’re living in the moment; they’re doing it. And I think as long – for those people who are just getting by and just doing it, if it works for them, then I think sometimes that’s okay. We cringe, but then I’m not the one living with the chronic illness (HP8).

Obviously if you’ve got a knowledge of something that’s unsafe you need to address it, and that’s our professional responsibility. And how you manage that is variable, I suppose. But if it’s a safety thing, then you need to address it and document it ... But if there’s just that lack of capacity to actually understand just how detrimental this is to the child, then you have to, it becomes a CYFs thing and we have got CYFs involved in various things (HP2).

There was no clear-cut point of change between novice and expert caring; rather, it was a process of development: “... it’s not like a thing that just happens, it’s steps all the way, steps of learning, and learning and refining and learning again, and learning and getting new perspectives on it, and learning and learning and learning” (FC17). Initial attempts to differentiate an intermediate learning stage between novice and expert carers produced very similar categories for the intermediate and expert stages, the difference being a matter of degree. Hence an intermediate stage has not been defined, but while the endpoint is being expert, material in this section also reflects the process of becoming expert. The features of be(com)ing expert are ongoing learning, clinical competence, adapting to life with technical health procedures, interfacing with medical and other systems, teaching others and experiencing the costs and benefits of caring.

**Ongoing learning**

Expert carers competently performed technical procedures day-to-day, but they were aware of some limitations in their learning, particularly with regard to managing things learnt in theory but not yet put into practice and dealing with new problems that arose. Continuing education included further aspects of procedural management,

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2 Child, Youth and Family is a New Zealand government agency which works with families, including having a statutory child protection role.
deepening clinical knowledge and problem-solving. These were sometimes acquired through additional professional teaching, but also developed from carers’ experiential learning and from further information sources such as the internet and other carers.

The best example of ongoing professional input was that for families managing type 1 diabetes, who had regular outpatient clinics (with a doctor, nurse and dietitian) and teaching including more complex dietary management and being “coached on how to begin the calculation process [of adjusting insulin]” (FC9B). They could also access optional seminars and support groups which included professional input. However, for the other carers in this study, professional teaching largely ceased after the initial phase, except on an ad hoc basis at the carers’ request. For instance, one carer discussed changing a PEG, something she had been taught but not yet had to do:

I’d do it, because I’m quite good at remembering those sort of details, but then the longer it’s been since I learnt it, and it’s only ever been in theory anyway, a little bit more, kind of, “Oh, do I know how to do it?” so maybe I’ll ask for a refresher. But that’s it – you sort of ask to be shown (FC10).

In addition to any professional teaching, carers were learning from their own experience, using observation, making deductions and some “trial and error” experimentation (FC14, 18, 22). Other carers and the internet were again important sources of information (and reciprocal sharing), particularly for practical advice. Through their learning, carers continued to adapt and individualise procedures and manage problems.

Problem-solving ranged from sorting a procedural difficulty to figuring out practical matters like how to keep a dressing dry in the shower or what to do with all the rubbish. While health professionals might be most concerned about recognising and dealing with problems that have the potential for clinical harm, carers were also dealing with these pragmatic issues and the reality of managing a problem in the sometimes less-than-ideal, non-clinical setting.

Interviewer: So does she stay hooked up the whole night [to a feeding pump]?
Carer: We did do that, but again, because she is really mobile, which again I’m really grateful for, but it sort of doesn’t work very well with the pump because she wriggles all around in her bed and it just started coming out. Every single night it would come undone, and so every single day, entire bedding getting washed and everything and we were getting no sleep, and I’m like, well can we just
do it – like we increased the day feeds, decreased the night feed and made it a bit faster so it takes about two hours and we just put it on when, once she’s asleep, fast asleep, we put it on, and then about two hours later, we’d turn it off, and that’s normally when we’re going to bed anyway, so that’s good (FC10).

I think a lot of the important things we learned about tube feeding were more through other parents so it was another parent who said to me, “Use an elastic band to hold the syringe onto the side of the cot rather than holding it in your hand” ... and then later on, it was another parent who said to me, “Look, you don’t need to have the pump taking up the whole of the tray underneath the pushchair, you can actually hang it from the handles.” And that was a very simple thing, but it really changed our lives because it meant we could do so much more. So I think that might be the kind of thing that perhaps the nurses and things don’t even know ... because they know their stuff very well, but they don’t actually live with it. So like the stoma nurses were very good, but because they don’t actually live with it, things like that sitting backwards on the toilet [to empty the stoma bag] they might not be so aware of. They’re doing much more the technical changing pads and things (FC18).

Health professionals described giving ongoing teaching both proactively (particularly in regard to more complex diabetes management) and reactively when requested by a carer. Further teaching included new material (such as moving from “very simple first-line advice when they’re diagnosed through to teaching them to do fairly complex carbohydrate counting so that they can then use that to adjust their insulin doses” (HP9B)) as well as the reinforcement of earlier teaching, particularly aspects of a procedure which had been taught in theory but not yet experienced or practised by the learner. In addition, health professionals were aware the initial “overwhelming amount of material” (HP4) might not all be retained so needed “refreshing” on later occasions. Where learners had been given relevant written material, it could be referred back to at this point.

So you kind of try to say, “If it blocks, or if it does this, this is what you do.” But unless it’s happened to them, sometimes that information won’t go through. So I’ve got families who ring up quite often with things that’ve gone wrong and it’s the first time it’s happened and then you can talk them through it. You probably told them it may happen, but they still ring up and they still don’t quite know what to do, even though you’ve explained that to them. So having information written, obviously, for all those kind of things, and having that contact person saying that this is all stuff that will
happen, but if you’ve got any questions about any of these things, you still can ring us or ring your community nurse or whatever it is (HP2).

Another aspect of ongoing professional teaching might be helping carers with problem-solving and developing their own clinical reasoning. Thus instead of simply telling the carer what to do, three health professional participants described asking questions like, “Well what do you think we, you should do?” (HP9B) or “What was happening that you felt this was needed?” (HP11) then helping the carer work through making a decision.

Finally, in one interview, the two participants talked about having a role of giving experienced carers advice which permitted them to simplify procedures and affirming their ability to trust their own judgement (with the potential for conflict with other professional advice):

And we’ve had families who’ve come here where the child, the parents have got to get up at 5 o’clock to start the feeding and they’re still there at 12 o’clock at night. Now to me that is so wrong ... [and] we’ve seen so many children like this, they keep vomiting it back up because they’re not tolerating it, the tummy’s not able to cope with it because it’s too big a volume ... I say, “Look, why don’t we be sensible about this? Why don’t we work out what you intuitively as a mother think?” ... And parents would say, “Yeah, I want to do that, but the dietitian’s telling me this.” “Why don’t we leave it and do what you think’s right?” So we then, rightly or wrongly, we have empowered parents to make this – now I know parents who are still so guilt-ridden, they come here, they say, “I tell the dietitian this but I’m doing this.” And to me that’s sensible. However, that’s not telling that professional person actually how it is. They’re not getting it. They’re not getting it, and they should be getting it... And people don’t know that they don’t have to – you know, the [gastrostomy] site can be treated just as a mouth; you don’t have to have all these sterile syringes and stuff that we’re wasting, and it’s okay to do this and okay to do that. So I do a lot of teaching, lots of teaching like that for families and lots of things that families haven’t, somehow or other, they’ve missed out on, about how you do this or how you do that. ’Cos the system hasn’t given them the information, or the time to process the information before they go home. So we’re constantly telling parents, “You can get a liquid for this medication so you don’t have to crush this, or you don’t have to do that.” “We don’t know that. How come I’ve been doing this for five years and nobody’s told me?” So we do that quite a bit; quite a bit. So that would be where our teaching would be (HP10A).
Clinical competence

Through their ongoing management of technical health procedures, expert carers developed well-honed skills which became automatic and finely-tuned to individual need. In addition, they demonstrated advanced clinical decision-making skills, including the use of monitoring.

In this research, carers were not observed managing technical health procedures, but their competence was apparent from their descriptions of what they did. For example, in the following quote, a mother explained how she managed her daughter’s cecostomy. Though originally “they sent you home with a booklet on how to do it,” this had long since been consigned to a drawer and she had her own routine down pat. In her familiarity, she abbreviated some steps in her description (for instance, she did not mention opening or closing the outflow from the bag, or disconnecting things at the end). She had also had to problem-solve and customise the procedure (its frequency, the composition of the washout fluid and the impacts of diet) for her specific child:

So she has the little opening in her tummy, little coil button, you just open the button, have a connecting tube that you put onto that and that’s connected to a bag, that’s the bag there [pointing]. We only use 400 – that’s what works for us – we only use 400ml of cool, boiled water and a teaspoon of salt, and that goes through and that does her fine. Others use huge amounts; others do it every other day. I do watch her diet, though, because I try to keep her away from chocolate and acidy things so that doesn’t disturb how frequently she poos. So that works for us. It’s 400 ml cooled boiled water and every night for an hour she sits on the commode and just watches TV. And I just push her down to the shower, I clean out everything. It’s just become our routine; it’s just what we do (FC15).

With repeated performance, procedures became reflexive: “But she was pulling it [nasogastric tube] out four times a day so I’d stick it back in, so in the end, you can do it in your sleep” (FC14). Earlier expressions of difficulty and anxiety were now replaced by confidence and comments about the ease of the procedure: “I was scared before [starting to learn to manage a tracheostomy] ... but once, just a week or so, and then kind of [snaps fingers] it was, oh, I didn’t know it was this easy. Very easy” (FC12). Experience and confidence in their own clinical skills and judgement could lead to modifying techniques or dispensing with some procedural steps, such as no longer doing pH testing after replacing a nasogastric tube because “you can tell after a while” (FC22) that it was in the correct place.
Expert carers had highly developed knowledge of the precise needs and responses of the person they cared for, as well as an instant, intuitive ability to assess if anything was wrong. This specialist expertise contrasted at times with the generic skills of professionals, and sometimes had to be defended in the face of professional disbelief. Related to their clinical expertise, carers used medical and technical terminology with easy familiarity, including acronyms, abbreviations and drug names. They were also precise when required, for example, differentiating type 1 and type 2 diabetes, or specifying a Foley catheter.

So I go down her nose. There’s a spot, you’ve got to go down and round, then there’s just a little spot, I can’t really explain it, but you hit, and then that causes her to cough really deeply and then I can suction... I guess it was trial and error in a lot of ways and particularly in the early days. Now I know her so well, it’s like if I do one thing wrong, for me it’s apparent immediately; like I know I’ve done whatever, haven’t suctioned her enough or the feed’s running too fast or something, because I just know, almost without knowing, it’s weird. Certainly in the early days, it took a lot to get to know what she could and couldn’t tolerate and that sort of stuff (FC14).

Mother: There’s this tiny muscle between her top lip and her nose and I could look at that and I would know she was going to have a big seizure within half an hour. And I don’t know how, I couldn’t explain it, I couldn’t describe it, but I knew.

Father: ... It’s instinct. We could pick things up and say, “She’s going to be in trouble in a day.” And the nurse would look at you all funny...

Mother: You get that look as they went out the door of, “She’s got a bloody good imagination!” And we did. We got labelled as being ... dramatists. Well yeah, we were always right ... And I actually refused to leave the hospital one day. They were trying to discharge [my daughter] and I said, “We’re not going. She’s going to have a biggie soon.” And 20 minutes later she did, and she ended up in there for another three weeks (FC20A&B).

A further expression of clinical competence was monitoring the overall health of the care recipient and making decisions about adjusting care or seeking specialist assistance when required. Although some carers spoke of being taught about signs of problems to watch out for, it seemed they developed much of their clinical expertise from their own experience and interpretation. They demonstrated finely-tuned skills in assessing what was or was not normal for the care recipient and in interpreting clinical
and technical data. Even while sleeping, they could be attuned to detecting a problem. Some carers kept written records as part of their monitoring, to remember events and action taken, and to provide a way to assess patterns of behaviour and responses to treatment. Written records also provided information to share with professionals.

Interviewer: So how can you tell that she needs it [suctioning]?
Carer: She starts foaming at the nose and she gets really distressed when she’s not been suctioned enough because she can’t breathe, really. And her sats [blood oxygen saturation] fall. Because she’s on a sat-monitor overnight and her sats would sit really low and if she’s suctioned really well, her sats are 99[%]; if she’s not suctioned well, her sats are in the 80s, so it’s really easy to tell ... [At night] it’s funny, we can have a massive storm, lightning, and people say to me the next day, “That was so loud!” and I’m like, “I didn’t even hear it.” But her sat monitor beeping, it’s like immediately I’m awake; it’s bizarre.

Interviewer: So you’ve got a finely-tuned ‘mother’s ear.’
Carer: Yeah. And also her breathing. Like I can tell, ’cos she’ll start [makes sound of distressed breathing]. With her ultimately her sat monitor will beep, but I can hear that [breathing] before I hear the monitor (FC14).

Another type of monitoring was supervision of the care recipient if they were self-managing aspects of care, to ensure things were being done on time and correctly:

[When] we left the hospital, I was helping her do that [blood sugar] test. It’s a small finger pricker and she has to put a drop of blood on a little test strip and it probably wasn’t too long before she could do that herself. So that was quite a quick part, but obviously mentally the part of caring for that is to remind her to do it. You know, she’s still at an age where those things don’t automatically go off in her head, so it’s just always being one step ahead of her, morning, lunch, afternoon tea, dinner and bedtime, so five times a day, and so just reminding her, “Do that test” (FC9A).

Notwithstanding their expertise, expert carers still had limitations to their skill or knowledge and they might make mistakes. Even these could become learning opportunities.

She had a massive coma episode where she just wouldn’t wake up so she was rushed to hospital by ambulance and they said she wouldn’t survive, she was so septic, and we didn’t know what was wrong with her, but it turned out after massive tests and all kinds of stuff, they realised she had a really horrendous urinary tract infection. Because her urine had been smelly for about six months, but someone had told me somewhere along the line that in children with disabilities, once
they get to about five, their urine changes in smell and becomes a bit stronger, so I just thought the change in smell was ‘cos – ‘cos she wasn’t, no temp[erature]s or anything like that; she wasn’t febrile. And that’s what we’ve learnt now – [she] doesn’t get temps with UTIs. And it wasn’t bothering her, so I didn’t think anything of it (FC14).

Health professionals also recognised the clinical expertise which carers could develop and acknowledged the intimate knowledge carers had: “It often comes to the point where the carer knows more about the patient and how to do the cares than we do ... They have that 24 hour, seven day a week knowledge and watchfulness that we don’t get” (HP3A). Professionals accepted some modification in techniques by carers, provided these were not harmful. In turn, expert carers monitored the care of health professionals and could be “very critical” (HP6) about the techniques and standards they expected. At the same time, health professionals also had expertise, including broader health knowledge and clinical skills; therefore, each party needed the complementary expertise of the other, a point which will be considered further in the section on carer-professional relationships.

[During a hospital admission] the parents are actually teaching the nurses, and they’ll be very, very strict on what the nurses are doing to their child if they’re already doing it at home. They come in, and if the nurse is doing it different to what they think, because they don’t have that kind of, because sometimes there are a few ways to do that, so they’ll question things, which is really important that they question it, so make sure they understand there’s more than one way, but the principle’s the same (HP2).

Ongoing adaptation to life with technical health procedures

Novice carers began to adapt to life with technical health procedures, including developing family rules and routines. For expert carers, routines were well-embedded, as demonstrated by this mother’s response when asked to describe a “typical day” caring for her daughter.

I get up about seven, or start getting her up about 7.30[a.m.]. First thing I do is disconnect everything, take off the sat[uration] monitor and the feed pump and all that, and then I, if she’s done poos, I clean her up, wash her and everything, and then I catheterise her and dress her for school, do her MicKey button dressings and then put her in her chair and put a nebuliser on which takes 20 minutes to run through. After that, I do her hair, do her teeth, and then she goes to school. To me, that doesn’t take that long. Then after school, she
comes home and I don’t really have to do anything until about 5 [p.m.] – oh, I do her medication[s] in the morning too, sorry, meds about 7[a.m.], and then she needs meds at 5[p.m.], so between 3.30 and 5[p.m.], she just watches TV or she’ll go in her standing frame or if she’s tired, she’ll have a lie down in bed. Then if she’s on gentamicin twice a day, she’ll have her neb[uliser] at 5[p.m.] and then her other meds and generally I try and put her into bed by about 6[p.m.] because she is quite tired, but she doesn’t go to sleep. She’s got a communication device and we’ve loaded it all with her DVDs onto the device, it’s like a computer, so she lies in bed and watches her TV and sometimes she’s still awake to 11[p.m.], but she’s happy. So then, put her back into bed at 6[p.m.]; she’s had her meds. Then I do her catheter again, change her dressings again, put her into pyjamas, put the sat monitor on again, put her [feeding] pump on, put the CPAP on if I’m using it, give her a good suction, and then that’s it, pretty much. And then I just wait for her to beep! So that’s a day at school. And then a day at home, the only change would be she has meds at 12 [midday], and then the two other catheters. Meds at midnight. So it’s not too, well I don’t think it’s too bad... Most nights, I would be up probably two or three times to her, but some nights it can be eight or 10 times, depending if she’s got a cold or what’s going on, then other nights I might not get up to her at all, she might just sleep through. But by and large, I get up every night, and I would say on average two to three times, for a suction or a reposition or reposition the mask or reposition her head (FC14).

In time, managing procedures became normalised for carers as “just part of our life now” (FC7), although comparisons with others could reactivate awareness of difference: “... in the end it becomes just your new routine ... and it’s only really if you’ve got to teach it to somebody else or if you’re explaining it to someone else that you realise that you do more than most people” (FC18). They hoped others would also accept their normality rather than viewing procedures as a cause for alarm or avoidance. Health professionals also recognised the normalisation carers developed through repetition, and even used this to advantage in teaching. On the other hand, one health professional expressed concern about carers becoming so acculturated to their own situation that they no longer recognised the magnitude of what they were doing or what help they might need, and that health professionals could take carers’ work for granted. Similarly, a family carer gave an example of the consequences of losing the ability to judge what was ‘normal’ or not.

When you have a child with special needs and even if they are really complex needs, as a mother, after a while it all becomes normal ... [For example], the child whines most of the time and you can only stop it by doing this and this. And if the child whines only 10 hours
out of the 12 hour day that you’ve got, then you think this is really
good. And that goes on for a while so you think, “Well this is all good
and this is all okay.” So then when I go with this mother to a needs’
assessment or to a doctor’s appointment and they say to the person –
this is true – and they say to the mother, “How do you manage?” And
she says, “Oh fine, fine, everything’s fine, it’s all good.” So then the
person starts to think, “Well gosh, there’s no problem here,” and then
I say, “But hang on a minute, your daughter whinges da da da and this
and this and this,” and she says, “Oh yes, but she’s not so bad.” And I
said, “Yes, but most 10 year olds don’t do that.” And that’s when they
say, and they’ve said this to me, “Actually, you’re right. I’ve got so
used to it” (HP10A).

We got to the stage that we didn’t know what we were doing was so
abnormal. We had gone to such a level of expertise that we didn’t
understand that we had actually gone way outside what people
normally think, and we got in trouble when our youngest [non-
disabled son] started getting really bad asthma, and according to us,
he was coughing, and yes he was struggling to breath, but he was still
breathing enough, and we had to go, he ended up in hospital ... and
they actually sent us to an asthma educator because they needed to re-
educate us to the boundaries of normality so that we didn’t allow him
to get so bad and yet to us ... it wasn’t so bad, he was still breathing,
hadn’t turned blue; he was doing okay. If he’d turned blue I would
have panicked, but he didn’t. So that was a real eye-opener. And even
now, we struggle with [our disabled daughter] getting sick and us
tolerating it because it’s in our boundaries and most normal families
would be having kittens (FC20A).

**Interfacing with medical and other systems**

Another role apparent among experienced carers was interfacing with medical
and other services. Working with the medical system involved knowing how to get
assistance when needed (the appropriate personnel to approach, including for some,
permission to bypass primary care services and access secondary services directly) and
negotiating treatment options (for two, including alternative therapies). In order to do
this, carers became medical informants, able to communicate with and coordinate
different health professionals.

I mean, if we’re taking [our son] to an After-Hours [clinic], I go with
this folder [I keep updated] and they’ll ask me his medical history and
I’ll pull out his medical history and say, “Look, just read it.” …
Everything’s there (FC21A).

For parents, a common interface was with educational services, advocating for
their child’s inclusion and appropriate care, providing information and organising
training for staff. Other systems carers had navigated were respite or residential care, vocational services, Work and Income New Zealand and ACC. A frequent task was advocacy for their family member (“She has no voice, so I have to be her voice” (FC22)), including advocating for treatment and services, and social respect and inclusion. Sometimes carers also advocated for their own needs. Advocacy required confidence and skills, as well as time and energy which not all carers have; nor was their advocacy always successful.

[After struggling for some years with a school that refused to manage technical health procedures and constantly called this mother in to help:] I said to [my husband], “We have to move him. It’s not working.” So we approached [a specialist education school] and it was there that they started doing – I mean, I was quite adamant I was not going to be called. I was not going to go and be called all the time. And [the principal] agreed with me and I just said, “Your staff have to be trained in insulin injections and blood sugars. They have to be trained in the feeding and all that stuff. The just have to be trained in it” (FC21A).

I was getting ill from the stress of that [attempting to obtain a piece of equipment], and that nobody listened, nobody was interested. It was just horrendous. We should have gone to Fair Go or something, but I didn’t have the energy to do that. I was looking after him at home; I was exhausted, you know. You don’t have the energy to pursue that stuff when you’re just trying ... [to] get by on daily life, yeah, and you’ve got other children at home (FC17).

**Teaching others**

Having developed expertise, some carers then became teachers. Even as novices, some immediately became teachers for other family members; this was the case for several mothers who were professionally taught how to manage a procedure for their child, then on-taught their partners. Later, some carers taught other members of the family (such as grandparents and even other children in the household). In time, some children learnt to self-manage a procedure, and much of this teaching was done by parent-carers.

Beyond the family circle, carers taught babysitters, respite carers or school staff. They could also find themselves having a role educating the general public (about health conditions or disability broadly rather than specific procedures) in response to misconceptions or the curious stare in public. Finally, some carers even taught health professionals, such as nurses at a respite facility or as when this mother took her
daughter to their general practitioner, who said, “‘To be honest, this is the first port[a cath] I’ve ever seen. I’ve never dealt with one.’ ’Cos that was when they were fairly new. So it was like, that was really helpful! I ended up teaching him, going through the procedure and showing him how the port worked” (FC20A).

Teaching others and giving them responsibility for a procedure involved some risk to the care recipient, so carers were cautious about whom they entrusted with this role. They also wanted the recipient to be comfortable with alternate carers.

Carers expressed mixed feelings about their teaching expertise. This might reflect both uncertainty about competence as a teacher (none mentioned any training for this role) and awareness of the limitations of their expertise. Some expressed a preference for professionals to do any teaching, while others wanted to pass on their expert knowledge of how a procedure should be tailored to the specific needs of their family member.

Also what ends up happening is that, my partner works, but he has to be able to do it too, so I learn it and then I teach him. And he’s not the type to research it himself or pick up the book and read the instructions – it’s probably quite typical! But I guess it would be nice if there was a way they [nurses] could teach him without me being there, so that it was sort of like, you know, he was taking responsibility for it. I mean he does, he does do the feeds, but ... it’s set up in such a way so that I have to teach him, but there’s still bits and pieces it’s kind of like, “Well I’ll just do it my way anyway” and it’s like, “Well, this isn’t my way, this is the way it was taught.” So I think there’s some gets lost in the filtering through, because perhaps you know, perhaps my partner might see, you know, a nurse or a doctor as more of an authority on how to do it whereas I’m just, you know, not a medical professional (FC10).

I did the teaching [of school staff], mainly because I find that I know the way [my daughter] likes, I know how she likes to be catheterised, how she likes to be suctioned, whereas the nurses will come in and tell them by the book what to do, but I say, that might work for some, but it doesn’t work for [her]. So what we tend to do, we try to do it in conjunction. Because the school like to know what they’re doing is not doing any damage. So the nurses will come in, but then the nurses will even say, “What mum says is fine, so just do what mum says.” So we try and do it in conjunction (FC14).

Carers observed a similar pattern of learning in others to their own experience, with people going from initially being “petrified ... [to] actually pretty confident” (FC21A) once they had learnt. Carers generally taught as they had been, by showing and explaining what to do then giving opportunities to practise under supervision. One
had created a ‘stoma’ in a doll to use as a teaching aid and some added written material, either resources they themselves had been provided with or material (including pictures) they had specifically developed. In the case of teaching other children in the family, there was natural preparation through “just the watching and the normality of it” (FC16) and in the process, learning by osmosis.

**Experiencing the costs and benefits of caring**

Expert carers carried most of the day-to-day responsibility for managing procedures, which could at times be “quite a weight” (FC8). However, one mother reflected on a positive aspect of the authority she held as a parent and experienced carer to use her discretion, as opposed to the carers at her son’s residential facility who had “just got to follow the regime ... and if you don’t follow it, you get into trouble ... It doesn’t leave much room for people’s initiative” (FC17).

Carers mentioned a range of costs associated with their caring, including physical, emotional, family, social and financial costs. Carers shouldered ongoing care and responsibility, even if respite care was available, and often lived with uncertainty about future life and care for their family member.

[My husband] and I are physically buggered. My back has had it, my shoulder needs re-building, one hip is really bad, his back’s gone (FC20A).

I got really depressed ... I had this newborn baby, I was still really, really unwell. I had this sick, sick, sick kid, who I had so much work to do, and I got to the stage where I pretty much stood in the middle of the road crying, because I had so many things to do and I couldn’t do any of them (FC20A).

Initially, everyone [in the family] went on hold for two years nearly, rugby went on hold, [the other] kids weren’t doing anything, kids weren’t going out anywhere, it was home, home, home (FC19).

It’s obviously, it’s closed a lot of our world, it has, socially ... We actually did lose a business ... [when I] had that 6 months wait [caring for child in hospital], and it was just too much, we couldn’t afford to have somebody else there, so we lost a business (FC7).

It chased away all our friends – they couldn’t cope with all of this stuff. I mean [my daughter], you’d be halfway through a conversation and [she] would go into status [epilepticus], so we’d just sort of deal with it while still chatting, and they couldn’t handle it; they’d get upset and leave (FC20A).
However, a technical health procedure could at times mitigate some costs of caring, and might even be a catalyst for personal growth in other ways:

[A nasogastric tube] took a lot of stress off me and it turned an hour and a half of getting in 50 ml to five minutes for getting in 50 ml, so it made a huge impact on my life and my other children’s life because you’ve also got to consider your other children when you’ve got one with special needs. And it can actually impact them more than you realise (FC5).

Carer: It’s been hard, but it’s been the making of me, though ... 
[T]his has really made me look at myself and say what really matters in life, and to really reassess where my priorities lie and my values lie and that kind of stuff, and I’ve found that really, yeah.

Interviewer: So that’s been a positive.

Carer: It really has, and I’m a better, sounds so clichéd, but I’m a better person for looking after [my daughter] and everything, because I just have a different appreciation – I don’t take anything for granted any more. Every day is a gift, and even my health and [my other daughter’s] health (FC14).

Health professionals recognised caring could be costly for families, and this could be exacerbated by inadequate support both from within a family (for example, one person being expected to carry the major care load) and from professional services (both in terms of limited in-home support and opportunity for respite). Conversely, they saw that good support, including information about entitlements for other help, could reduce negative impacts on carers.
D. Carer – professional relationships through the learning journey

As has already become apparent, carers’ relationships with professionals changed as they moved from being novices to becoming experts. This section further explicates the evolving association between the two parties.

Initially, health professionals held greater knowledge about managing a technical health procedure and, in their teaching role, began to pass this on to the new carer. Carers needed and valued this professional expertise and their support in learning to manage new roles.

Once carers were sufficiently competent to manage day-to-day, regular professional input generally began to reduce. Sometimes this happened immediately following initial training; other times there was ongoing support with a gradual reduction over time. The exception was type 1 diabetes management, where professional teaching continued through regular outpatient appointments, although here too children and their carers were increasingly in control of day-to-day management.

Carers could contact professionals on an ‘as required’ basis for further advice and support and to obtain equipment supplies (although after-hours access was limited for some and could mean dealing with unfamiliar personnel). However, despite access to some professional assistance, a few carers expressed a sense of abandonment once they were managing competently. For example, a couple managing a very intense and complex intravenous drug regime for their daughter were assured before discharge from hospital that they would have professional support at home, but this did not eventuate as they expected.

We were promised faithfully that we would get a lot of help. We wouldn’t be on our own; there would be people every day coming in to assist. We’re still waiting for them to turn up ... ’cos the district nurses came and kind of threw up their hands: “Oh God, we don’t know about this sort of stuff; this is really beyond us.” ... Disappeared again. But sort of said, “Oh call us when you need more syringes and things” and that was the end of that ... We tried getting some carers through the Carer Support3. We tried to hire people, and everybody took one look and went, “Yeow! Not doing this!” (FC20A)

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3 Carer Support is a subsidy funded by the Ministry of Health to enable unpaid, full-time carers to obtain respite care services in order to have a break from caring themselves. Eligibility and the amount of Carer Support are determined through a Needs Assessment and Service Coordination (NASC) process. (See http://www.health.govt.nz/your-health/services-and-support/disability-services/respite-and-carer-support/carer-support)
Carers were now taking more responsibility for their own ongoing learning and in addition to any professional education, they learnt through their own experience, from other carers (in person on online) or from information on the internet. As carers grew more confident in their own ability and judgement, they started to assess health professionals’ competence and question their advice. They might choose to ignore or override advice with which they did not agree or knew was actually wrong. However, this required assertiveness and not all carers would be able to challenge professional power.

I used to feel ... like I’m getting fobbed off, and I’d accept what I’m being told and I’d go away ... I’ve had time to be strong enough and get over the, “Oh, they know what they’re doing. Who am I? I don’t know anything, I don’t have a degree, they’re the experts, they’re the doctors.” Whereas it’s taken a time, now I know they were no more expert than I was, and we’ve come along together, but at the end of the day, I’m the expert, so now when things do go wrong, or something happens, I can say, “No, this is – “, and you can force those second and third opinions (FC19).

For health professionals, decreasing their regular support for carers and moving to reactive rather than proactive contact was a practical necessity of their workloads and having to prioritise needs, as discussed by the district nurses in the quote below. In limited situations, a nurse might offer ongoing hands-on support with part of a procedure (such as replacing a nasogastric tube, while the carer managed regular feeding) or additional assistance on a temporary basis “when things are in crisis or coming to an end” (HP3B). However, all the health professionals stressed the availability of professional back-up when required by families, including in person as well as by phone, text or email.

Interviewer: So is it really a resourcing issue for your service as to how much you can keep going in?
HP3B: Yes, definitely.
HP3A: It’s freeing up our availability to take on new referrals. We don’t have a wait-list; we respond to every referral ...

Interviewer: Do you have a cut-off, discharge point? ...
HP3A: If people are self-sufficient, then we will often say to them, “Well how about we just ring you once a week for the next couple of weeks?” Then at that point we will say to them, “Well we’ve rung you for three weeks; you seem to be doing really well, you haven’t needed us. If in the future you need the district nurses to come back
again, then contact your GP and they can easily re-refer you.” ...

HP3B: Basically we say, “We’re not going to pull out until you’re comfortable doing it.” But we will pull out as soon as you’re comfortable doing it, you know!

When carers had become experts and their expertise was appropriately recognised by health professionals and vice versa, the two parties could act in partnership. Each had different but complementary expertise: carers, an intimate knowledge of a care recipient and how to manage a technical health procedure specifically for this person; health professionals, the ability to draw on a broader knowledge and skill base. For an effective partnership, each must be aware of their own skills and limitations and trust and be willing to learn from the other, as reflected in the examples below from both carer and professional perspectives. Developing mutual recognition was easier in ongoing relationships where “we’ve all learnt together” (FC19) than when suddenly having to deal with new personnel, such as “when you strike the A&E [Accident and Emergency department] and random doctors and nurses that don’t know us, because they go by the book, and that’s when you’ve really got to sort of, you know – I know they’re qualified, but I know what I’m doing” (FC19).

I think if professionals could always realise the parent is the expert in their child and how their child will cope ... and then the good nurses will say to you, [ask] how best to deal with him through this situation. So that’s where the parent is good, in knowing what the child, how the child will deal with things. [And also, she later explains, with knowing how to manage procedures in the context of daily, home life.] ... But the medical staff are best at knowing what medical procedures should happen – or you have to hope they are! [Laughter] You basically have to trust they are, you know. We’ve had times when – I can remember with the ENT surgeon saying, “I think she should have grommets” and I really didn’t think she should, and in the end having to say to him, “Well, I’ve come to see you, so I’ve really got to do what you say, haven’t I!” So I think in a way parents need, both sides need to understand their boundaries (FC18).

Carers gave examples of having their expertise recognised. However, they also spoke of distrusting professional proficiency at times and of having their own expertise devalued or, conversely, taken for granted. The mother below reflected on the double jeopardy of having her expertise both disregarded and assumed:

But you actually become so skilled at what you do, that other people look at you and go, “Oh smart arse, what do you know?” and that’s a real thing with medical people – “What would you know?” ... But
then once they do recognise your expertise, you're on your own, because they leave you to do everything (FC20).

Partnership and recognition of mutual expertise related not only to carers and health professionals, but also carers and professionals in other spheres, notably education staff in the case of parents whose children’s technical health procedures needed managing at school. While some parents had taught school staff, other schools were reluctant to accept parental advice, seeking input from health professionals instead.

While carers’ expertise needs to be rightly recognised, they should not be inappropriately relied on beyond their skill level and they still appreciated professional support for the responsibilities they bore. Although expert in the nuances of caring for their family member’s particular procedure, carers were also aware of their limits. In situations beyond this, they sought and expected professional advice and assistance. While recognising that professionals were learners too (“they had the learning curve as well as we did” (FC21A)), carers expected them to act professionally and acquire knowledge and skill when necessary. The two quotes below contrast a positive example of learning shared with a professional, and the abdication of this responsibility.

I remember when I was interviewing my GP to see whether I wanted her as my GP, she said, “I don’t know anything about [your son], don’t know anything about his condition, but I’m willing” and I thought, “I’m willing to have you as a GP if you’re willing to learn, then we’re going to learn together” ... If they’re willing to learn, just like you are, you move on. You build up relationships (FC21A).

I think that was probably one of the lessons that I had to learn too, was that when you go to a medical professional you need to know what you’re doing. Like I’ve had doctors ask me what medicine I’d like to give her. And I was like, “Ah actually, isn’t that what you went to med school for nine years to tell me?!” Like hello, that’s why I’m here! One of the times was when she had bad seizures. And really, looking back in hindsight, that doctor really didn’t have much of a clue. He’s a paediatrician, you know, he’s the expert [but prescribed medication a neurologist at a later appointment considered inappropriate] ... they’re not God, they don’t know what’s the best for everyone and they make mistakes (FC16).

Carers with previous health profession training might begin with on a more equal footing with the professional teacher, if the carer’s own professional background was recognised, as it was in this instance: “The district nurse said, ‘Oh you can do this’ and I said, ‘Right, just give me the gear’” (FC1). On the other hand, even those with
prior training might be novices with regard to a specific procedure and be aware of their need for teaching. In addition, the caring role was being carried out primarily within the family relationship (for example, as parent or partner) rather than in a health professional capacity, so the experience of managing even a familiar procedure could be very different.

The first thing would have been giving medication and because I had a nursing background already, I was a Registered General Nurse, that wasn’t any kind of issue at all ... Then the next thing along with that was his bowel care, because we noticed that very early on, that he was prone to having some issues with bowel function, so dealing with constipation became an issue, and that was one thing having come from a nursing background to know what to do; another thing on an emotional level, trying to help my son to do a normal bowel motion when it was hurting him and upsetting him and very painful, so emotionally it was very difficult for me and it was like, this is much harder than being just a nurse that you were removed from the patient. It’s quite different (FC17).

Ultimately, for some expert carers with ongoing relationships with professionals, these could become like friendships too, although there was still an awareness of boundaries:

I’ve been very impressed on the whole [with health professionals] ... They usually do seem quite good at having a relationship where – well, I suppose it just is a relationship. It’s almost a friendly relationship, because actually, a lot of your support does come from them. Once you’ve got a sick child, then you’re involved in hospital stuff a lot. It’s quite easy almost to forget that they are doing a job, you know, so they have to keep some kind of boundary (FC18).

**Summarising the process of learning technical health procedures**

The initial teaching of technical health procedures varied depending on the procedure (in particular, its complexity and risk profile) and what the learner was perceived to need and want to learn. In addition to which aspects of a procedure were taught and by what methods, teaching also differed as to where it took place (in hospital and/or home settings), who delivered it (a specialist or generalist teacher) and for how long. Assessing and mitigating risk were important considerations for health professionals with their more clinical focus, while carers experienced an emotional learning journey in addition to its intellectual aspects. The teaching process was
individualised, but with the common goal of ensuring the learner was sufficiently competent and confident in managing the procedure.

At that point, novice carers took on primary responsibility for the procedure and carried on learning and refining their technical management, in particular, how to cope with causing discomfort. In addition, they were adjusting to a new world of illness or disability and its impacts on their family situation.

As carers gained experience and developed expertise, they continued to expand their learning through experience and by information seeking, in addition to any further professional teaching. Expert carers demonstrated well-developed clinical skills and specialist knowledge about the person they cared for. They adapted to life incorporating technical health procedures, including by using routines and normalisation. They could develop skills in advocacy or in teaching other people to manage a technical health procedure. All this came with a mixture of costs and benefits to the carer.

Through the learning journey, the roles and relationships between carers and health professionals changed. The control of procedures and self-management of learning by carers became more prominent as regular teaching by health professionals decreased. Ideally, a partnership developed in which each recognised the other’s expertise for the patient’s benefit.
IV. Embracing care

Alongside and overlapping the learning process, another process was occurring, namely ‘embracing care.’ This concept of embracing care describes how family carers experienced and responded to taking on the role of managing technical health procedures. Within the overarching concept, there was a spectrum of five positions which carers could adopt, namely: accepting embrace, resisting embrace, reluctant embrace, relinquishing embrace and being overwhelmed by the demands of caring. These positions were not static and carers commonly moved between them. The positions were apparent in the initial round of interviews with family carers and further confirmed and elucidated by the interviews with health professionals. This section explains each of the five positions in turn along with patterns of changing embrace. It also considers the context in which embracing care occurred and the way preparation (or its lack) influenced carers’ experience.

Accepting embrace

Accepting embrace was about carers’ willingness to take on managing a technical health procedure. This is illustrated by the quote below, in which a mother explained how she came to be feeding her child through a nasogastric (NG) tube and her expectations about a planned gastrostomy (PEG):

Well basically it was me that said I want the NG. I want this ... We kind of had her feeding, but it was very, very, hard work and in the end it was just, I was just, “No way, I just can’t do this.” It was too hard and she was not gaining weight and that wasn’t good for her so we just opted with that [nasogastric feeding] ... I’m really excited about getting the PEG [laughs] after all this time because it’s not nice having an NG all the time on her face and for her skin and just in general, having to put it down her nose is not very nice for me. And then we can focus on more oral feeding because I think the tube, the tube tends to also, like it affects her swallow and her gag, so I’m looking forward to that next step ... I guess when you look at it in the big picture, you’re doing it for a good reason. You’re doing it so she’s going to grow and have the right nutrition, so it is benefiting her. It’s not that you’re doing something unpleasant for no good reason if you know what I mean. It’s not something I enjoy doing, but it’s for the better, so I don’t really look at it as a negative thing ... I just think these [pointing to packets of tubes] have saved my daughter’s life and if you look back 20 years ago, they used to teaspoon milk into
children who couldn’t [feed]. These are just the best thing invented really (FC5).

This example demonstrates a very positive embrace of both procedures as being in the child’s best interests (indeed, lifesaving) and making life easier for her carer too. While replacing the nasogastric tube was unpleasant for both mother and child, it was viewed in its wider context as being done for a good purpose. The planned gastrostomy was already being embraced as it was expected to provide additional gains and a step towards other goals while reducing the disadvantages of a nasogastric tube. Overall, this mother had an appreciation and acceptance of the benefits of the technologies.

While the term ‘accepting embrace’ has positive connotations, this need not imply the carer enjoyed managing the procedure, as noted by the mother above. Further analysis revealed there were shades within this position, from an unquestioning trust in professional advice or expectations (“I just felt I offered myself up to the health professionals to tell me what to do” (FC9A)), to pragmatic acceptance (“I guess [my husband] and I both have the attitude that it is what it is, and if you can’t change it, there’s no point stressing about it. Just feeding her myself wasn’t working so we had to do something that worked” (FC22)) to the active embrace of the first example above, and finally to post-hoc embrace:

It took me a long time before I reluctantly embraced the PEG idea. And it wasn’t until the PEG went in, and honestly, within days I could see the change in him – his alertness increased, his skin was better, he started to put on weight, he started to enjoy life, he was happier, and ... when I saw the change in him, I felt really dreadful, I felt really guilty and really bad that I hadn’t acted earlier, because it had been suggested to me, but I rejected the idea (FC17).

For carers, the primary motivation to embrace managing a technical health procedure was the need and expected benefit for the recipient. At the same time, the recipient could not self-manage the procedure or over time, ceased to be able to self-manage as “circumstances change” (HP8). The ‘other side of the coin’ was that the existing situation had become untenable and this could impact on the carer as well as the recipient. Hence accepting a technical procedure could have spin-off advantages for the carer (for example, making feeding quicker and easier); however, at other times, it meant additional work for the carer (such as managing home peritoneal dialysis) and coping with the downsides of the technology (for instance, responding to a machine alarm in the night or always needing to have equipment with you on an outing). An
additional motivation for a family member providing care was that it meant there could be a timely and convenient response to need, rather than having to wait for and fit in with professional assistance.

The interviewed health professionals identified the same motivations for carers accepting embrace, and added three more they occasionally saw. The first was a financial imperative. Where the alternative would be residential care, family members might choose to provide care at home to avoid potential costs or loss of income. In this instance, embrace might not be ideal for either the recipient or the carer.

Some of that [deciding to take on caring] is around the funding too, though, I think – children or family members trying to keep people at home, for financial reasons, not wanting to lose the family home and that’s where some people’s motivation comes into it. It would be a big loss of income for them for the family member to go into care, so they’re very much very keen to step into the carer’s role... Sometimes I have to say that situation is to the detriment of the patient, the care they receive. The person can’t quite meet their needs, but equally neither party can walk away from the situation (HP3A).

Secondly, some adults might abrogate their responsibility to manage their own care and expect another family member to assist them, either from the outset or sometime later.

[There are] some patients who choose not to change [a stoma bag] because they can’t face it. And generally we will try negotiation with them as well. Sometimes the carer chooses then to just do it, pick up that role, just because, I don’t know whether that’s maybe the way their relationship works (HP7).

One further angle of embrace, albeit infrequent, was the carer who was perceived to ‘over-embrace’ their role and, in order to retain this, emphasised the medical needs of the recipient and their own part in providing specialist care. Here, the carer’s needs had overridden those of the recipient.

We’ve got parents who are so hooked into that kind of, this is the medical uniqueness of my child; I’m going to have sterile syringes and I’m going to have everything and ... I’m going to do everything by the book. So you go there and they end up telling you, “This is how it has to happen because this is how the nurse said or the doctor said or the dietician said” and there’s no leeway and the feeling behind it is ... guilt. So we have some families who totally medicalise that situation... There is a group of people, there are people who love it, they love the nasogastric tube, they love the fact that, “I’ve got to put the nasogastric tube down, I’m not a nurse, I’m not a this, and my child has to do this” and they show everybody and they worry about it
... and I look at them and I think, “You could make your life so much easier [by taking advantage of ways to simplify the care]” ... And there’s a lot of kudos to the fact that on my doorstep has to arrive these special drugs and special nappies and special milk feeds and I’ve got to have them all lined up and there’s a lot of kudos ... They thrive on it. And if that child dies – God forbid – they lose that kudos (HP10A).

Carers might embrace the management of a technical health procedure in whole or in part. There were four components of embrace: cognitive understanding of the purpose and benefits of a procedure; accepting a ‘technical’ solution; practical management; and an emotional response. The mother in the initial example in this section understood the reason for nasogastric feeding, had a very positive view of the technology and had learnt the skills for both feeding through the nasogastric tube and replacing it when necessary. Her affective response held in tension having to do something unpleasant to her daughter with promoting the child’s overall health. However, other carers might not embrace all these components. Comprehension might be only partial, at least initially. Carers might resist or only reluctantly embrace a procedure when they did not accept its benefits outweighed any perceived disadvantages or they were opposed to ‘unnatural’ treatments (see further below). Carers might choose to learn how to manage some aspects of a procedure but not others (for example, feeding through a nasogastric tube but not replacing it if it came out). Lastly, one’s affective response influenced how easy or difficult it was to embrace managing a procedure – in the example below, parents discussed their differing initial feelings about giving their child insulin injections:

Mother: Horrible. It’s –
Father: I was just the opposite. No problems at all. Because it was either that or dire consequences. So it was an easy reaction.
Mother: No you see, I didn’t like it because she didn’t like it and sometimes she’d get upset by it ... there’s that feeling of especially if she’s a bit teary and she didn’t want it and she cried after it, you just wanted, you know, you’re a mother and you just inflicted pain on her, and it’s not very nice (FC9A&B).

Reframing perceptions of a procedure and indeed the whole life context might facilitate a more positive affective reaction. Examples of this strategy included choosing to accept life as it is (“I guess I always knew from the very beginning that [my daughter] was never going to be normal so I just took everything as it was at face value
and accepted it” (FC14)); focusing on the benefits rather than unpleasant aspects of a procedure (“We’re not hurting them, we’re helping them, so it was that change in mindset” (FC8)); downplaying the magnitude of the procedure (“It’s not that big a deal” (FC6)); or viewing the situation favourably in comparison to others (“Heaps of people have worse things to deal with than us. Just get on with it” (FC8)).

Finally, in order to be open to embracing a new procedure, carers might also have to let go of existing patterns and expectations. This could also be associated with a grieving process:

’Cos MicKey buttons are quite an emotional topic for a lot of people and one of the most normal things to do in life is to eat [orally] (FC16).

He had a small wheelchair I think about four or five [years old] and that was hard, because I mean the therapist came in with this little wheelchair, and I was like, “Oh, oh my God, my son is going to be in a wheelchair.” And all my hopes, I suppose, and dreams that one day he might walk just went boom, gone. And so there was a big grieving (FC17).

Resisting embrace

Carers who resisted embracing procedures remained unconvinced of their clinical benefit, did not believe it should be their role or did not feel they could cope with managing them, and/or had not (yet) been able to reframe a negative emotional reaction associated with the technology or perhaps the overall clinical situation:

She had the NG tube in the neonatal unit, and they thought she would have to go home with it, but I was just, I didn’t understand what was happening, what had even happened to her, but I was like, “No, she’s breast-feeding and she’s bottle-feeding, why do I need this?” And she didn’t need it in the beginning. But I remember them trying to show me putting it on the litmus and I was just like, I refused to learn it because I didn’t want to do anything like that ... And I wasn’t in the right space to learn it then anyway. If she had really needed it, I’m sure it would have been different (FC10).

Someone having a hole with a trache, I was like, “No! I won’t do it. Do it the way he is. I don’t think I’m going to manage with the hole; that is too much” (FC12).

Three carers gave examples of others they knew who had resisted embracing procedures: “I know this one lady who will fight to the death before she gives her [child] a MicKey button” (FC16). All used this metaphor of fighting, reflecting the
strength and energy that might be exerted in resisting and the sense the procedure had been negatively framed as an enemy rather than a potential friend. In addition it reflected a lack of trust in health professionals’ recommendations.

Health professional participants also recognised the resistance of carers who were struggling to accept the need for a clinical procedure or who did not want to be the one to manage it. This resistance might be expressed directly or manifest though passive resistance and a failure to comply with professional directives:

Well you can tell some people aren’t going to do anything ’cos they don’t do that, and when they don’t get in and help. They won't jump up and help. You know, you have to really lead them to do it and then when you’ve actually gone through all the process and the next time comes, they’re still sitting there [distant] when your patient’s there [close by], and then you’re beginning to think, “Oh dear, perhaps this isn’t going to work out” (HP12).

Health professionals added a further expression of resistance to embrace through the inability or unwillingness of a carer to manage to a safe standard:

We’ve got a few parents who fall into the ‘neglectful’ category so we have interaction with CYFs ... We’ve actually never had to remove a child for that but we’ve come close and we’re close at the moment with one family, but generally another person in the family will pick that up through a CYFs intervention, a family group conference (HP4).

Finally, resistance might also come from the recipient who could be reluctant to accept help from family members generally or a particular individual (for instance, a mother might not want her son to provide intimate care).

Being able to resist embracing care implies there is an acceptable alternative: the procedure can be safely rejected (at least for a time) or someone else (another family member or a health professional) is available to manage all or some of the procedure at home. However, the necessity for a procedure might become more critical and a carer might then choose to accept to manage it (willingly or reluctantly); if they remained resistant, this might precipitate their relative moving into alternative care.

Carers were most likely to resist managing aspects of a procedure which were distressing for the recipient. For example, they might be willing to feed through a nasogastric tube but want a nurse to replace the tube if it came out. However, this resistance was sometimes worn down over time by the inconvenience of getting outside help or its lack of timeliness, and by familiarity increasing carers’ confidence to self-
manage. Embrace could thus shift and enlarge over time, as illustrated below from both the family carer and health professional perspectives:

I decided to not learn how to put it [nasogastric tube] in, because it was such an awful job and I didn’t want to be the one doing that to her all the time. But if it had, I think if we’d gotten past how long it did take, I probably would have learnt sooner or later, because it did become a bit of a pain to go in and out [to hospital] to get it done all the time (FC22).

Like I can think of nasogastric tubes and [the carer is] like, “There’s no way I want to put that down! I would never do that!” But as time goes by and they see you doing it and then they think, and then sometimes it’s the weekend and they think, “Oh this is a nuisance, we’ve got to get the kid in [to hospital for tube replacement], maybe I’ll – ” so they come round to it in their own time ... I think if they see something done often enough, then I think it sort of normalises things after a while, I suppose, and then they think, “Oh yes, it’s no big deal. It just pops down the nose into the tummy. That’s no big deal, I can do that.” Or just the convenience of it (HP6).

Health professionals described three responses to carers who were resisting embrace. Where this resistance was perceived as legitimate (for example, their work or living situation precluded availability to care), they provided additional professional services if possible or encouraged alternative family care; however, if neither was possible, this could result in a move to residential care. Where they felt a carer could appropriately learn, they attempted to overcome resistance and encourage embrace by providing additional information about the need for and benefits of the procedure along with support and reassurance for the carer. In the event of real or potential harm to a patient, they took action to ensure the person’s safety.

**Reluctant embrace**

A further point on the spectrum of care was reluctant embrace. In this position, carers again expressed uncertainty about whether the purported clinical benefits of a procedure outweighed any negatives. However, they reluctantly accepted professional advice because they thought they should, the alternatives appeared even less acceptable or they felt they had no choice. Alternatively, while accepting embrace of the need for a procedure, carers might only reluctantly embrace managing it themselves, doing so again because there was no better choice.
And they also wanted me to add a calorie supplement to the milk, and I was very reluctant to do that because of all the information I’d read about upsetting the baby’s gut. But we did it, reluctantly.

Interviewer: What moved the balance for you, that you did do it?

Carer: Because she was still losing weight. And I guess at that stage, the doctors were still in the position that they know best and so we did it, but it took a long time to see any weight gain (FC22).

A further reason for reluctant care was dissonance between cognitive understanding of the benefits of a procedure and one’s emotional reaction to it:

I know if I take all the emotion out of it, it’s saving her life, so I just have to tell myself ... but it just seems so unnatural. I think, when she’s older, I wonder if she’s going to need that? ... I think, “How would she manage that?” (FC15).

Health professionals agreed lack of alternative care options could compel family members to reluctantly embrace caring, and family expectations might impose the care role on a particular individual. From the health professionals’ perspective, carers could also be reluctant to embrace because they were fearful of being left to manage alone or concerned that becoming involved in one task would inevitably lead to more responsibility. They attempted to counter these concerns with reassurance about their ongoing support:

You’re learning how to do the skill, but it doesn’t mean we’re not going to be in contact, so I think at that point, that’s when a lot of family members or carers say, “Actually, yeah, I do feel safe and supported in this.” I guess that’s the other – a lot of families worry that by taking on certain cares, they’re going to lose the support of our service, so that’s another motivator or reluctor, a point of reluctance for them ... And there’s a reluctance to saying, “Yes” initially to learning because they wonder where the buck will stop. “If I say yes to doing this, are they going to make me do everything?” you know (HP3A).

Relinquishing embrace

Carers and health professionals identified four situations when carers might temporarily or permanently relinquish the role of managing a technical health procedure. Firstly, care might no longer be required – the clinical need for the procedure had resolved (for example, a stoma was reversed), the recipient learnt to self-manage (although a carer might continue some supervision) or the recipient died.
Secondly, the carer or recipient might perceive the disadvantages of the procedure as greater than the clinical benefit and choose to cease the treatment. Thirdly, carers might reach a point where they no longer felt able to manage and substitute care arrangements had to be made. This might occur right at the start of a technical health procedure (resistance to managing the procedure becoming the tipping point for the recipient moving to alternative care) or after a period of caring at home. However, while daily hands-on care might be relinquished, emotional concern and oversight of the quality of the alternative care continued.

Fourthly, carers might temporarily relinquish care if their family member was hospitalised or in respite care or, in the case of children, during time at pre-school or school. Respite benefited carers by allowing them time for a break and to attend to their own needs but some found they were expected to continue providing technical care even while their family member was in respite, or chose to because of concerns about safety and quality.

With both temporary and ongoing alternative care, the recipient’s needs were generally privileged over the carer’s, with carers willing to forego respite if its quality or acceptability were in doubt (“We don’t want her to be homesick, so we brought her back home... Ever since then, we’ve just cared for her at home” (FC11A)). However, carers in two families had reached a crisis point where, for the sake of their own health needs, they had become willing to accept less-than-satisfactory residential care situations (albeit whilst continuing to seek improvement). As well as carers having confidence in the quality of alternative care and knowing the recipient was happy with it, successful respite for these families also depended on the general availability of alternative care (“Specially in a rural place like this ... there’s no homes, there’s no respite facilities, there is nothing” (FC20A)).

Other family members were commonly trusted to provide respite care, including the primary carer’s partner, parents, siblings or adult children. Even younger children from the age of 10 provided help with procedures, often while the primary carer was busy but still available for supervision, though occasionally young siblings took full responsibility. However, not all carers had other family members who were willing and able to assist with care.

Technical health procedures, and concern about their risk (whether accurate or not), could create a barrier for potential respite personnel being willing to take on care: “People are petrified of it” (FC21A). Hence families managing this type of care
sometimes found respite services difficult or impossible to obtain. An alternative was to arrange care at times when technical procedures could be avoided, but this was not practical in all situations, or at least limited respite to short periods. Even when temporarily relieved of hands-on care, the family carer retained overall responsibility and remained ‘on-call’: “My cellphone sits in the pocket and you get beeped” (FC21A).

For parents, having their child at preschool or school provided some respite from care, as did day programmes for adults. However, once again, these services had to be willing and able to manage technical health procedures when necessary. Carers related experiences of both readiness and reluctance by schools and services to take on this care:

They offered at school: “Would you come in and show us how to do this [PEG feeding] so we can do this for you so you can do what you need to be doing during the day?” ... we’ve been so lucky with this school (FC19).

[The school staff] just said that they weren’t medically trained to do it [insulin injections] ... And I said I could train them, I could get an educator to train them, a nurse, but they didn’t want to do it ... And it was a nightmare, because I felt like there were days when I was being called all the time to school ... I was constantly at beck and call (FC21A).

The experience of relinquishing care will depend on how carers perceive the reason for relinquishing. Thus ceasing a procedure because the recipient’s improving health renders it unnecessary might bring the carer a sense of freedom and reduced stress, while having a loved one die, or move into residential care because their needs have increased beyond the carer’s capacity to meet them might create more mixed emotions.

Health professionals sometimes encouraged carers to relinquish some care for the sake of their own needs. However, they were aware this was difficult when the alternatives were unacceptable to either the carer or recipient, and that there was potential for conflict in relationships. The financial implications sometimes made relinquishment problematic too.

And sometimes we’re given the job of saying, “Actually we can see this is going to be too hard for you to manage” when the ... [carer] doesn’t want to actually say that to their [family member]. So the patient’s not managing; would like to go home. The carer is saying to us, “I’m not going to be able to do it.” And we can be the mediators (HP12).
Overwhelmed by the demands of caring

At times, carers could feel that rather than choosing to embrace a technical procedure, the demands of caring overwhelmed them. One participant described this as feeling “like a mouse on a running wheel – no matter how fast you run, you’re not getting off the running wheel” (FC20A). Another illustration of this experience was given by a participant who described a day caring, from helping her relative get up in the morning to going to bed at midnight. The two pages of transcript follow the pattern, “Then ... and then ...” (with 27 repetitions of ‘then’) culminating in, “Then the same thing again the next day” (FC11A). Unlike paid health professionals who might experience intense demands during a work shift but then have a break, family carers might have to be available for care continuously.

When carers were overwhelmed, the care role might overtake other aspects of identity: “Now that she’s older, it’s definitely just a small part but when she was younger, it seemed all-consuming. It seemed like you weren’t the mother, you were the nurse, basically. There was no other time, it seemed, to be doing anything other than toileting” (FC15).

Being overwhelmed by caring could be temporary, particularly during a crisis, or more ongoing where daily care was intensive and there was little support or respite. The environment and social attitudes also contributed to or relieved the sense of being overwhelmed by care. For example, the lack of accessible facilities impeded a family outing and schools, described by some parents as welcoming and willing to accommodate their children’s needs, could also impose obstacles to a child’s attendance, as noted earlier.

One participant alluded to the possibility that being overwhelmed could be self-imposed through both attitude and choice about the level of caring. However, though carers might be able to choose at times between ‘best’ care and what is ‘good enough’, interpretations of what is adequate and acceptable could differ.

I find some people quite ‘anal’, I guess is the best way to describe it! Like they get up twice during the night to test their kids [blood glucose] and things but you don’t have to, unless they’re sick and stuff like that, and people who are just over the top fusspots about it, constantly at school, constantly; they’re moaners, and it’s all just hard (FC8).
Health professionals noted that one way to reduce the risk of carers becoming overwhelmed was to encourage as much self-care as possible by the patient. “If we get the person themselves able to do most of it themselves, then it becomes less of a burden [for a carer]” (HP7). In addition, professional support and respite played important roles, as illustrated by the contrasting experience of the two carers below:

It was a really nightmare time, and looking back, had we known what we were in for, we would never have agreed. If the back-up we’d been promised had happened, we’d have been fine. But we were absolutely beyond exhaustion (FC20A).

The district nurses were my back-up, though. If ever I had got sick or couldn’t be there, they knew all about it and they would come and do it. But we never needed that. That was good. But it was a good back-stop (FC4).

As noted in the preceding section, being overwhelmed might be a catalyst for the carer to seek change and even relinquish care. Though the ‘last straw’ need not be a technical health procedure, the addition of even a ‘small’ procedure needed to be considered in the context of the whole family and care situation, as one health professional reflected: “I think doing the technical stuff is part of a huge picture and sometimes doing the technical stuff may just be the tipping balance” (HP11). Conversely, a technical solution to a problem sometimes relieved carer stress (such as a urinary catheter making incontinence easier to manage).

**Changing positions and boundaries of caring**

In describing the five positions within the concept of embracing care, it has already been apparent that these were by no means fixed. Common movements were from resistance or reluctance to accepting embrace, and from accepting to being overwhelmed, reluctant to continue or relinquishing care. Where accepting embrace brought clear advantages to the recipient, this confirmed the decision to embrace, whereas when benefits were not fully realised or problems developed, carers might reconsider their options.

Shifting positions could be related to changes in the intensity of caring and the availability or absence of appropriate support or respite. Having accepted a caring role, it might be assumed carers would automatically do more if required, or they might make a pragmatic choice to take on more for the sake of convenience and being able to
provide a timely response to need. However, the provision of additional professional support could also reduce the demands on a carer, although professional support in the home was partial and intermittent, and might be used to sustain greater ongoing carer involvement, as in the example below.

I can manage the [wound] dressings, but in the last few months the district nurse has been coming to do them simply to, it’s just something less that I have to do... When I was starting to do his dialysis for him ... it was decided that I had enough to do, I didn’t need to have to do that [dressing], that was one thing they could do for me (FC2).

Shifting embrace was also related to the concept of boundaries of appropriate care. Both carers and health professionals set boundaries, which were individualised according to what carers were willing and judged safe to manage. Initial boundaries might later move. For example, while one carer expressed willingness to “give anything a go” (FC4), another could not imagine doing a further procedural step because “I just don’t think a lay person would ever do that” (FC3) and he was happy this was instead managed by a nurse once a week. Yet he hinted his boundary could move: “I mean, if I had to do it on a daily basis then I’d, you know, inquire about whether I could do it myself”, suggesting, as noted earlier, that convenience and a growing familiarity were important factors in choosing to accept or extend embrace. A third carer’s experience illustrated a retrospective view that her boundary of care should have been reduced rather than expanded. In this instance, professionals initially set a boundary that would not allow home management of a technical procedure, which the carer and her husband persuaded them to change. Later, realising the enormity of what she had undertaken, compounded by the failure of promised professional support at home to eventuate, she re-evaluated her choice:

Carer: I think it is nice that we had the opportunity to do what we did, but looking back it, it shouldn’t have happened; it really shouldn’t have happened. [Our daughter] was really far too sick for parents to take home, and they should have somehow made an agreement where they had medical people coming to our home to look after her. It’s what should have happened. We should never have been allowed to do what we did. It was dangerous; it really was dangerous, and we knew that. We pleaded for it to happen, but parents aren’t always the best judges of what should happen. Sometimes they need to be told, “No.” We don’t regret doing it, ’cos it gave us
the time that we needed as a family, but we were put at risk. I mean, like to have to get legal documents to absolve you of criminal responsibility is going too far...
To be honest, I don’t think we had any idea what we were letting ourselves in for, and how it would grow. Because it was like Topsy – once it grew, it just kept growing.

Interviewer: So in a sense too, having accepted something, then there’s sort of an expectation that you’ll just carry on.

Carer: Yes, it’s like, “They’re good at this; let’s give them that as well” (FC20A).

A health professional agreed carers’ circumstances and their ability to care could change, and affirmed the need to periodically check, rather than assume, their willingness to continue:

And you find that families often make that commitment [to care] when someone’s relatively well without recognising actually as the disease progresses, what that entails ... I check it out with family members: “Are you still okay doing this? Have you got any concerns?” And if they do name concerns, and depending what the concern is, I’ll address the concern and say, “You don’t have to do this.” ... ’Cos people get exhausted. It’s not a static thing. What was okay this week may not be applicable next week (HP11).

The context of embracing care: relationships, choice and preparation

Having set out the five positions of embracing care, we also need to consider again the context within which these occur: at home, within family relationships. Family carers had a prior and continuing relationship with the recipient and one that extended beyond managing medical needs to knowing and loving the whole person: “I think the medical part is part of [my son], but it’s not the whole package. To me, the whole package is this bubbly 23-year old who enjoys life” (FC21A). Another participant reflected on her varied experience of the caring role – but always underpinned by her commitment to her daughter:

At times it’s empowering that you have taken control and you’ve done something magical and it’s always all about, it’s not about you as a parent – it’s about the one you’re caring for. It’s about giving them better life, or better opportunities or better standard of care or more love. So sometimes it feels really good that you’re doing it. But other times you resent the hell out of it, because you really want to go to bed and you’re just exhausted, and you can’t! And sometimes you want to throw your hands and say, “I just can’t do this anymore.” But you have to (FC20A).
The context of ‘choosing’ to embrace care is thus constrained by being set within relationships and the associated assumptions that family members, especially parents, should naturally care, shaped and reinforced by cultural beliefs and the expectations of professionals. Knowing that “you’re not the only one and other people do it” (FC15) also normalised the expectation that carers should manage technical health procedures at home.

It’s your kid, it’s your responsibility. He can’t do—he depends on you, so you have to have that mind, you know, that you have to help him, no matter what happens and to remove the emotion or “Why did it happen to me?” That one, just put it aside, forget about that and see he has not done anything in this world, he just came this way and it’s my responsibility to take care of him (FC12).

There was no ‘ifs, buts, oh, oh’—you just had to do it ... they [professionals] just randomly rabbit off that this will be it and you just do it (FC15).

There are few alternatives to family care which again limits choice about taking on this role. Some family members are unable or unwilling to help, leading to another member being ‘elected’ carer. Professional in-home support is limited and might not be available on a timely or convenient basis. For adults, there are residential care options (which might be more or less acceptable to families), but very little out-of-home care for children now exists in New Zealand. A final unpalatable option might be withdrawing treatment and accepting the consequences of this.

In their interviews, professionals presented a mixed discourse about the choice to care. Alongside discussing expectations family members would care and the limited alternatives to this, they presented other narratives of unpressured choice and the ability of carers to opt out of (some) caring and be replaced by additional professional support.

Interviewer: I was just going to ask if you think there’s anything carers shouldn’t be allowed or expected to manage at home?
Health professional: Anything they don’t feel comfortable with, you know, and I think we just need to listen to them, because I suppose they’re high risk because they’re caring for someone else, and I suppose this would be the same in the adult world too, but I think we just need to listen to that and be accommodating to that because that’s when people do harm, when they’re not actually wanting to do it (HP2).
Health Professional 3B: We can’t provide that 24/7-type care ... so unless there’s someone to fulfil that role, our service can’t manage them at home ...

Health Professional 3A: From our very first visit to patients, we begin assessing what family members can take on ... so from the first visit, you are completely eye-balling the carers, the family members, anyone who’s in a supportive role, for their ability to provide that support. And there’s always cases where the family aren’t willing or able.

Interviewer: Yeah, tell me about that ...

Health Professional 3B: ... we provide a service for house-bound people. We also run a clinic, so people who are able to get out and about but still require the services that we provide, we’ll ask them to come to the clinic, so that might be a situation where we ask someone to come to the clinic to have the injection, so they’re making the bigger effort to make it happen, and sometimes that’s enough to for them to reconsider whether they might like to do it for themselves.

A second contextual issue for embracing care is the degree of preparation carers have for taking on this role. The data presented a mixed picture about how preparation influenced embrace.

Among carers who had had the opportunity to prepare for a new procedure, all had ultimately come to a position of embrace. For some, prior preparation (in one instance going back to information given prenatally) had clearly been helpful: “So I think it was good for us to have been already well-prepared that that was going to happen so it was no surprise” (FC6).

In other cases, carers expressed strong initial resistance to a suggested procedure, gradually moving to reluctant embrace which became more accepting if they experienced advantages: “She started gaining some weight and it all became a good experience” (FC16). However, it should be noted that the opportunity for preparation also created worry about the anticipated change and its outcome: “I was scared, I was so scared of [my child] having the operation” (FC19).

In contrast, a procedure begun in an emergency situation offered little chance to prepare. Nevertheless, it might be positively embraced as life-saving. For example, a mother whose child developed type 1 diabetes said of the subsequent insulin injections, “It’s life or death, you have to have it” (FC8). Overall, clear clinical need and post hoc benefits were most likely to facilitate embrace, whether or not advance preparation was possible.
One participant was able to reflect on her experience of two procedures begun with and without preparation:

A lot is about the way you choose to approach the situation, and possibly the longer you have to prepare, then that helps your approach. I think certainly if you want your child to have it, that’s easier, like us wanting [our son] to have his gastrostomy. That’s very different to suddenly having a boy with an [emergency] ileostomy. But again, probably keeping the big picture, you know, which is that this child has life because of this, is quite important (FC18).

**Linkages between the learning process and embracing care**

The process of learning to manage technical health procedures and embracing care were interwoven, although the connections between them were variable and not predictable. The willing embrace of a new task or role meant carers were more ready to learn and, from the health professionals’ perspective, easier to teach: “Teaching itself wasn’t too difficult, but he was really, really motivated” (HP5). Conversely, carers who were resistant or reluctant were harder to teach and their disinclination to learn might then result in poorer quality care.

I mean, some of our families are really onto it and they make sure that they research and read and meet other families and kind of absorb new technologies, and often they’re the ones that will move onto a pump, insulin pump, they’re really motivated. And then there’s other families that just never really embrace diabetes management, none of them really want to manage it well, and those kids don’t tend to do very well. (HP4)

As the learning process continued, initial positions of embracing care could change; as noted earlier, carers could become more accepting of their role or vice versa. Regardless of their level of learning expertise, all carers needed sufficient support (from both informal and formal networks) to be able to sustain their caring without becoming overwhelmed.

Carers who had mastered managing one procedure could be more ready to learn another, but conversely, their lived experience sometimes made them more resistant or reluctant to taking on more. The following two quotes illustrate this contrast.

... initially, with the first things, you’re like, “Can I do it? Can’t I do it? I hope I can do it right.” You go through all of that. And then as you say, you master that. And then something else comes along, particularly the catheters, I, it never even occurred to me that there
would be any, that I wouldn't be able to do the technique. I mean, I understand she could still get infections and things like that, but from a technical, from doing it point of view, never, it was just like, “Yeah, I can do that.” And there’s been talk of her having a trache in the past – she’s fine now – and I’m like, “Yeah that’s cool”, it doesn’t even – and that is because I’ve realised I can master, and particularly having no medical background, so you just do it (FC14).

I had a really, really nasty incident with an EEG technician ... [in hospital, who] hooked up all the leads ... and then said to me, “Now in the night-time, this is the glue ... if the leads come off, you just do this.” And I said, “I’m not going to be here in the night-time; I’m going to stay somewhere different.” Because I had learnt that if you were there you worked 24 hours. And I was already exhausted with looking after this kid that wouldn’t breathe properly ... And I’m saying, “No! No! This is not my job. Get a nurse to do it.” ... But the expectation was, because I was good at this [other caring], that I would operate an EEG machine for them overnight, and it’s like, “Hello?!! Nooo!” This is not in my mother’s job description, no! Even if I had been there, staying for the night, I wouldn’t have done it (FC20A).

In short, while embracing care influenced the learning process and the learning process could lead to changes in embrace, each has to be considered and neither is static. The implications of this will be considered further in the following discussion.

**Chapter summary**

This chapter has given an account of the experiences of family carers managing technical health procedures at home. This has been described as a process of wayfinding, involving an extensive learning course as well as varying responses to embracing this role. Health professionals played an important role in guiding carers setting out on a new journey but subsequently, carers took charge of much of their own learning as they progressed from being novices to becoming expert carers. In the next chapter, the implications of these findings and their relationship to existing literature and theory will be discussed.
Chapter 5: Discussion

In the previous chapter, the detailed findings from this study were presented. This chapter summarises the study and its contributions and presents the grounds for its credibility. It then reflects on the findings in the light of previous literature, highlighting what they add to our knowledge about family care and considering their implications for policy and practice. Finally, the limitations of the study are noted and possible directions for further research are outlined before the thesis is drawn to a close.

Overview of the research and its contributions

This study set out to explore the experiences of family carers who manage technical health procedures at home and to develop theory about their learning process. Using grounded theory methodology and drawing on data from interviews with family carers managing a wide range of procedures as well as health professionals with teaching roles, an overall theory of wayfinding has been developed. Wayfinding invokes the metaphor of a journey. For the carers in this study, learning to manage technical health procedures for a family member was a new and often unexpected experience (even for those with a health professional background). A map is useful when venturing into unfamiliar terrain and indeed all the carers had received some initial formal training and support from health professionals. However, as the term wayfinding also implies, carers were at times pioneers in uncharted territory, finding their own ways to manage procedures in the context of their daily lives. While health professional advice and assistance remained available if needed, the ongoing learning journey was much more self-directed by carers who developed their own experiential knowledge and drew on advice from additional sources (notably other carers and the internet). With sufficient time and experience, carers developed expertise with particular procedures and an intimate knowledge of their family member’s responses, moving from initial anxiety to assured competence.

As will be seen shortly, these findings about the learning process of carers reinforce earlier studies, but this research has broadened the focus from a single procedure to the whole group of technical health procedures and delineated the stages of learning and their characteristics. This adds to the relevance of the theory for health professionals teaching carers, regardless of the specific procedure. In addition, the
second component of wayfinding, namely embracing care, has described the varying responses of carers to the experience of managing these procedures. Altogether, this research makes more visible an aspect of family care which has been largely overlooked in the existing literature on informal caring, despite it being perhaps one of the most demanding and skilful roles carers can undertake. Given population and health service trends, the shift to increasingly complex care in the home can be expected to continue. Therefore it is all the more important that the voices of carers are heard and their needs considered in the way health policy and services are configured.

**Credibility and usefulness of the grounded theory of wayfinding**

Claims for the credibility of the grounded theory of wayfinding are based first on having followed the methodological processes of grounded theory: sampling relevant populations, coding and comparing data from the outset, gradually building up the theory and continuing until saturation was achieved. The findings are thus well-grounded in the data (as illustrated through the use of quotations). They have been confirmed and refined through later interviews, discussions with my supervisors and research presentations. On a personal level, the theory has allowed me to reflect on my own experiences and see how they fit in a bigger picture.

Wayfinding explains the process of carers learning to manage technical health procedures and can be utilised by health professionals involved in teaching carers. I hope it is useful in increasing understanding of the learning process from the carers’ perspective, noting in particular the importance of emotional alongside cognitive experiences, the ongoing learning journey which extends beyond initial training (and may be largely unseen by professionals) and the development and valuing of carers’ expertise. Further implications of the theory are noted in the following sections.

**The research findings in relation to existing literature**

This section compares the findings with existing literature, highlighting both areas of commonality and new contribution. The overarching concept of wayfinding is considered first, followed by the learning process, relationships with health professionals and the spectrum of embracing care. The focus then expands from the individual to the broader context in which this caring sits, namely within the home
setting and straddling the boundary of formal and informal care. Each section concludes with recommendations for practitioners, health services and policy.

**Wayfinding by carers in the management of technical health procedures**

It is of interest that while health professionals provided initial maps and assistance with wayfinding, the navigational role largely devolved to carers after they took on day-to-day responsibility from managing technical health procedures at home and professional input became reactive rather than proactive. This is in contrast to models of health navigation which have been developing particularly in cancer care since 1990, with the aim of improving outcomes and reducing disparities in care (Freeman, 2004). A health navigator actively works with a patient to facilitate their access to health care throughout their cancer treatment. Two reviews of navigation studies with cancer patients have found improved screening rates, though less evidence of improvement in speeding up the time to diagnosis or overall outcomes (Paskett, Harrop, & Wells, 2011; Wells et al., 2012). A navigator programme has also been used to improve adolescent immunisation rates (Szilagyi et al., 2011) and been suggested as a model for early intervention with young people who have a mental illness (Bieling, Madsen, & Zipursky, 2013).

In the UK in particular, various models of key worker services have developed for families with disabled children (Carter & Thomas, 2011; Greco, Sloper, Webb, & Beecham, 2005, 2007; Sloper, Greco, Beecham, & Webb, 2006). Key workers also aim to help families navigate and co-ordinate services. A review of such services found families valued their support; however, there were no controlled studies of their benefits (Liabo, Newman, Stephens, & Lowe, 2001). In addition, not all families have access to such services (Greco et al., 2007) and parents themselves may end up as their own service co-ordinator (Kirk & Glendinning, 2004).

The rising incidence of chronic conditions and their demands on the health system have also given rise to a growing emphasis on patient self-management and the development of self-management training programmes (Battersby et al., 2010). More recently, a similar programme to train carers ran for two years in the UK (Yeandle & Wigfield, 2012). Compared to the health navigator model, these self-management programmes aim to develop patients’ and carers’ own navigational skills, reducing their reliance on the health system.
While finding one’s own way through may maximise carers’ skills and the individualising of care, there may be risks to both the carer and care recipient if ongoing professional support is insufficient. It seems ironic that programmes to encourage self-management and decrease dependence on professional heath care have developed at the same time as health navigation models which offer increased active support to facilitate better access to health care. Whether carers managing technical health procedures should be left to navigate their own way through and how they could best be supported in this role therefore remain open to further investigation.

**Implications**

- The concept of wayfinding and its implications for patient safety and quality of care, as well as the effects on carers, need further evaluation.

**The learning process of carers who manage technical health procedures**

In this thesis, learning to manage technical health procedures has been presented as a process with an initial concentrated period of teaching by health professionals followed by gradual development of expertise, largely through carers’ own experiential and self-directed learning. There was much about setting out on the learning journey which mirrored earlier literature. The concept of the expert carer has also begun to feature in the literature, but this study adds detail about the attributes of novice and expert carers.

**Initial training**

By definition, the technical health procedures in this study were going to be managed by family carers at home. It is notable, therefore, that much teaching took place in the hospital setting and without an assessment of the suitability of the home environment or how the procedure might need to be modified for that situation. Where the patient was hospitalised, and particularly when they could not be discharged until a carer was trained to manage at home, it makes sense to begin teaching in hospital. Teaching based in hospital or outpatient settings may also be a more cost-effective use of staff time than home-based training. Nevertheless, if this process were driven by the carers’ perspective, it would be tailored primarily to their needs which could necessitate
a radical reorganisation of services if training were to be home-based from the outset. For example, a patient with a tracheostomy would need to be cared for at home by 24-hour nursing services as family carers were being taught. This would clearly be costly, yet it would mean training was tailored to the environment and family situation in which it would continue to be managed. It would also obviate any transition from hospital to home or differences in the way the procedure is managed between the two settings.

Another benefit of prioritising teaching at home might be greater linkages with primary health care services which were largely absent in this study. The initiation, teaching and follow-up of technical health procedures sat within secondary or tertiary services. While some of these services offered 24/7 support, others had limited night or weekend backup, leaving carers to access help through a general practitioner or emergency department at such times. It is notable that primary health care thus features at times of crisis, with little prior involvement in day-to-day management of the technical health procedure. Even when general practitioners are familiar with a patient’s needs, there is a reduced likelihood of seeing one’s regular doctor out-of-hours. Stronger linkages could also be made with other members of the primary health care team such as pharmacists who play an important role in preparing suitable medication and advising about administration for people needing technical health procedures (for example, nasogastric or PEG tubes).

Another factor which influenced the teaching location was the teacher’s role and whether or not they were based in a hospital or community setting or could operate across both. This also affected whether or not learners had continuity of teacher or instead the involvement of multiple personnel, the latter carrying the risk of inconsistency between teachers (Mighten, 2007). It was not clear in this study why some procedures were taught by specialist staff (for example, home dialysis and type 1 diabetes management) and some by generalists (such as nasogastric or PEG/PEJ feeding); it may reflect historical health service or speciality development, or practical issues such as the volume of people needing to be trained. Comparison with arrangements in other countries would help in considering the optimal service configuration.

Considerations about the location and teachers of technical health procedures may be affected by how this training is framed: is it a patient-care task passed on by health professionals whose training was not primarily focused on teaching or is it an
educational process, underpinned by learning theory? Only one study was found which explicitly based a programme for teaching technical health procedures on a learning theory (Foster, 1993). This study applied Bandura’s Social Learning Theory to teaching parents to care for their child’s ostomy, thereby utilising observational and experiential learning and emphasising the importance of developing learners’ self-efficacy. A number of other learning theories (including behaviourist, cognitive, psychodynamic and humanistic learning theories) can also be usefully applied in health education, once again depending on and tailored to the learner’s needs (Braungart & Braungart, 2008).

In terms of identifying learners, health professionals seemed to focus on a primary carer and only teach other family members if they knew someone else was going to be involved or another person expressed interest. In particular, where a patient has to travel to access health services, generally only one family member can be funded under the DHB National Travel Assistance policy (Ministry of Health, 2009). An exception allowing for funding a second person can be made where “A second support person is required to learn technical skills for ongoing care of the client” (p. 20), but only when they “cannot learn these skills from a local health or disability support service provider, the first support person or the client” (p. 20). Among the family carers who were interviewed, several of the mothers had been trained then immediately became responsible for on-teaching their partners. Bracht (2013) highlighted the importance of including fathers in teaching about children’s care, both to support the fathers directly and to obviate mothers from having to teach them. To achieve this necessitates offering teaching at times and places that fathers (or other secondary carers) are able to attend. A series of papers about home enteral tube feeding (S. Evans et al., 2007; S. Evans et al., 2012; S. Evans et al., 2011; S. Evans et al., 2010) raised concerns about secondary carers who had been trained by the primary family carer rather than a health professional, suggesting they posed a risk to the recipient if their competence had not been assessed, although no evidence was presented that this risk had in fact eventuated. This also raises questions about responsibility for risk when technical health procedures are transferred from professional to family control, and who holds the expertise to teach others, issues which are considered in the sections below on boundaries between formal and informal care, and expert carers.

Both family carers and health professionals in this study described similar teaching methods, the most common being some variation of an explanation and demonstration followed by supervised practice. This hands-on and apprentice-style
teaching model was also common in the literature (e.g. Hendrix et al., 2009; Kennelly, 1987; Parmar et al., 1993; Townsley & Robinson, 2000). Simulated teaching was mentioned infrequently, and written material appeared to be an adjunct to oral and demonstrated teaching methods. Some carers were coached to develop problem-solving or decision-making skills through scenarios or discussion about their own experiences. Despite their limited training for a teaching role, health professionals’ reports of multiple methods and attempts to tailor teaching methods to carers’ learning styles accords with good teaching principles (Bastable, 2008). However, it was unclear how well health professionals assessed and addressed learners’ needs, including their health literacy which is known to be generally poor in New Zealand (Ministry of Health, 2010b). A particular issue was the lack of teaching materials in languages other than English.

Health professionals utilised both structured checklists and teaching plans customised for a specific person and procedure to guide their teaching. The best approach depends on how standardised a procedure actually is and whether standard techniques can in fact be translated unchanged to any individual and home environment. An optimum balance of these two approaches may be to provide guidelines for teaching with an emphasis on achieving outcomes (such as competency with particular tasks), allowing flexibility in how they are achieved. Evaluating the effectiveness of a teaching programme and considering quality assurance will require looking at the structure, process and outcomes of any programme (Donabedian, 2003; Worrall, 2008).

For family carers, learning these procedures was more than understanding and mastering a set of tasks; it was also an emotional experience to be caring for a family member, once again highlighting the relational context of family care and as reflected in other literature from the perspective of carers (Jerrett, 1994; Kirk et al., 2005; Levine, 1999b; Spalding & McKeever, 1998). Many of the health professionals in this study also recognised this and the need to therefore support carers as well as patients; however, some appeared to be primarily focused on the patient and the task of ensuring their needs were met (in this case, through the agency of teaching a family member to care for them). Such attitudes may also be shaped by health system imperatives to discharge patients as quickly as possible.

Some of the health professional literature is very task-focused with regard to teaching procedures, providing detailed lists of the clinical information and skills that
should be taught (e.g. Buzz-Kelly & Gordin, 1993; Hotaling et al., 1995; Vogel & McSkimming, 1983). However, emotions are recognised as influencing learning alongside cognitive factors and must therefore be considered in any teaching programme (Braungart & Braungart, 2008). A recent study highlighted the importance of supporting parent-carers to adapt psychologically to having a child with a tracheostomy as the first step to teaching them practical management skills (Joseph, 2011). Thus attending to carers’ needs is part of making sure the patient’s needs are also well-met.

**Implications**

- More work needs to be done to determine the best educational process for teaching family carers to manage technical health procedures, including assessment of the suitability of learners and their home environment, the location of teaching, assessing and addressing carers’ learning needs and health literacy, teaching methods and resources, and how standardised or individualised teaching should be. More resources in languages other than English are needed.
- Everyone who will be involved in family care needs to be identified and offered training at a time and place convenient to them. If carers are expected to on-teach others, they should be offered training and support for doing this.
- Further consideration should be given to how carers’ initial and ongoing competence are assessed, taking into consideration that competency in the home setting may differ from standard procedure in a hospital.
- For carers, learning is not only a process of acquiring knowledge and skills, but also an emotional experience and at times a stressful one. More recognition needs to be paid to carers’ own needs alongside achieving good care for the recipient. This could include stress management training.

**Novice carers**

Having been equipped with an initial map and sufficient training to take responsibility for managing a technical health procedure at home, novice wayfinders moved from following health professional guides to travelling solo, albeit with continuing contact with ‘base camp’. The transition to being in charge (often
accompanied by a shift from hospital to home) was noted as a time of some uncertainty, as in previous literature (Arras & Dubler, 1994; Henry, 2008).

Novice carers carefully consulted and followed the maps they had been given and these provided some security. At the same time, they began to develop their own routines and make adaptations due to their home context (its physical environment as well as other relationships and responsibilities) and the responses of the care recipient. In adapting procedures, carers used their own judgement as well as at times getting further advice from health professionals or other sources such as fellow-wayfinders and the internet.

For many of the participants, a particularly difficult aspect of caring was repeatedly doing something painful or unpleasant to their family member. The emotional connection between family carers and the care recipient and the stress of managing painful procedures has been commented on before (Furmedge et al., 2013; Jerrett, 1994; Levine, 1999b). Carers in this study described several strategies they used for managing unpleasant procedures: distancing emotions, reframing the situation, humour and seeking alternatives. Health professionals recognised that fear of causing pain was a barrier to carers’ learning and they attempted to reframe it as a necessary and beneficial procedure, to minimise pain as much as possible and to offer reassurance and support in carrying it out. However, health professionals seemed to be focussed on getting carers over the initial hurdle of doing something painful whereas carers also reflected on the continuing stress, even if they had mastered a technique. Here again the imperative to discharge patients quickly may be a driver for health professionals.

Abel and Nelson (1990) gave examples of carers blocking their emotional concern for a family member in order to care for them, or a family member with little emotional connection to the recipient being more easily able to do certain care tasks. This emotional regulation has also been noted as a coping strategy among physicians who likewise need to be able to deal with observing their patients’ pain and inflicting pain for therapeutic purposes without their clinical skills and decision-making being affected by the distress of the other person (Cheng et al., 2007; Decety, Yang, & Cheng, 2010). Reducing their empathetic response may also decrease the physicians’ risk of burnout, but this has to be balanced by the benefits of empathy in the medical relationship for both physician and patient (Riess, 2010). Achieving the right balance seems particularly problematic in family care, where emotional attachments are an intrinsic and necessary part of relationships between members.
Implications

- Carers should be offered support for learning to manage distressing procedures, not only in their initial training but also by checking how they are continuing to cope.
- Further research could explore the effect of inflicting pain within relationships and whether there is any risk that temporary and episodic distancing of emotions by family carers leads to more permanent disengagement with the recipient.

Becoming and being an expert carer

With time and experience, carers developed expertise in managing technical health procedures which rivalled and even exceeded that of health professionals. By this stage of the learning journey, initial maps such as written instructions had been filed away and carers competently carried out procedures automatically with well-established routines, monitoring and responding to clinical changes intuitively. While health professional teaching was focused on initial training, it was clear from this study that for carers, the learning journey continued, but became self-directed through practical problem-solving and through seeking advice from others (including health professionals but once again utilising the internet and carer networks). Technical health procedures were managed in the whole-of-life context (such as school and community activities).

The concept of the expert carer has been growing in the literature about caregiving (Allen, 2000; L. S. Anderson, 2009; Kirk & Glendinning, 2002; Kirk et al., 2005; Lowton, 2002; Mah et al., 2008; McNamara et al., 2009; Pickard et al., 2003; Robinson & Hunter, 1998). This study affirms the clinical skill (both practical and cognitive) of expert carers, their detailed knowledge about the care recipient and ability to navigate and advocate in health and other social systems. It also provides another example of the development of expertise, similar to earlier work about professionals (Benner, 2001/1984, 2004; H. L. Dreyfus et al., 1986; S. E. Dreyfus, 2004).

Others have drawn attention to the person-specific knowledge held by carers and their experiential rather than abstract learning (Abel & Nelson, 1990; Jayne Brown et al., 2001). Harvath et al. (1994, pp. 29-30) highlighted the value of both the “local knowledge” of family carers alongside the “cosmopolitan knowledge” of nurse in achieving good outcomes for the care recipient. Partnership between nurses and family
carers, with respect for both kinds of knowledge, also provided support for carers (Harvath et al., 1994).

An interesting facet of expert care was its normalisation and ordinariness within the family context, integrated through daily routines. These also featured in Beanlands et al.’s (2005) study of home dialysis. More broadly, normalisation has been defined as a strategy used by families in the general management of children with chronic conditions, involving both cognitive reframing of what is perceived as ‘normal’ and behaviours which support the family’s ‘new normal’ (Clarke-Steffen, 1997; Deatrick, Knafl, & Murphy-Moore, 1999; Knafl & Deatrick, 2002; Rehm & Bradley, 2005). However, in the present study, the ability by families to redefine their own new normal in relation to technical health procedures was challenged in contexts outside the home, such as interactions with educational settings or respite care. This suggests technical health care is viewed as being abnormal or extraordinary by those not accustomed to it.

Another feature of expert (and even novice) carers was their role of teaching others, such as family members (including children from about 12 years old), school staff and even health professionals, to manage the technical health procedure. This was not a role which any of the carers reported being trained for, and they presented mixed accounts of whether or not it was one they wanted – on the positive side, it allowed them to pass on their person-specific expertise, but it also meant taking responsibility for passing on the right information, which could be daunting in the novice phase.

Being able to teach also depended on carers’ expertise being recognised and trusted. In particular, some struggled to have their expertise acknowledged and valued by school staff and health professionals, who often recognised and trusted formal over informal knowledge. However, carers offer a valuable source of expertise to inform professionals. For example, the experience-based design movement draws on the experiences of patients and carers, along with those of professionals, to co-design improved healthcare services (Bate & Robert, 2006; Boyd, McKernon, & Old, 2010; NHS Institute for Innovation and Improvement, 2009; Pickles, Hide, & Maher, 2008). While focused on improving the subjective patient experience, the experience-based design process has also produced objective quality improvements such as reduced waiting times and improved patient safety (NHS Institute for Innovation and Improvement, 2009).
Implications

- Expert carers make a vital contribution to patient care. They provide the majority of daily technical health care, which enables the recipient to live in the community and relieves health services of substantial costs. Carers also have detailed knowledge of the recipient’s health and responses which is a valuable source of information for health professionals and could also be used for service design improvements.
- Consideration should be given to who (health professionals and/or carers) ought to be responsible for teaching other carers within and beyond the family, and how the competency of such carers will be assured.

Relationships between carers and health professionals

The development of expertise by carers was paralleled by changing relationships with health professionals. In the initial learning phase, carers depended on the knowledge and teaching of health professionals, but as the carers’ own expertise grew, the input from health professionals diminished. With mutual respect and recognition of each other’s expertise, they could work in partnership for the patient’s benefit. A similar pattern has been described in other literature (Hasselkus, 1995). Jayne Brown, Nolan and Davies (2001) referred to health professionals initially being “senior partners” (p. 31) in the relationship, possessing generalised medical knowledge which is vital as carers begin to understand a technical health procedure. In turn, carers develop and contribute their specialist knowledge of the patient as a person and management of the technical health procedure with this individual and home context (Jayne Brown et al., 2001). Each needs the other and the care recipient benefits from the contribution of both (Milligan, 2004). In particular, it should not be assumed that expert carers no longer need health professional support – on the contrary, particularly if the care recipient’s health or situation changes, carers may once again be novices needing advice and support (Beanlands et al., 2005; Jayne Brown et al., 2001; Nolan, 2001). It also means professionals should not abdicate their responsibility to provide clinical advice.

Effective partnerships between carers and health professionals require sharing of power; without this, carers may resort to employing subversive strategies to ensure their family member’s needs are met without threatening their care or relationships with
professionals (Beanlands et al., 2005; Heinrich, Neufeld, & Harrison, 2003). Carers, recipients and health professionals all stand to benefit if relationships are positive.

Expanding the patient-professional relationship to include carers poses some challenges for existing ethics of healthcare, which focus on individual patients and their autonomy and privacy (Lindemann, 2007). In contrast, Lindemann (2007) contends that in family ethics, “interests extend beyond selves”, “autonomy is relational” and “many confidences are shared” (p. 352-3, italics in original).

**Implications**

- If health professionals view carers as being on a learning journey towards developing expertise, they can consider what support carers need to achieve that and work in partnership with them to achieve the best outcome for the patient.
- Partnering with carers necessitates expanding the professional-patient relationship to include the patient’s family system.

**Embracing care**

To find your way through managing a technical health procedure involved not only a learning process, but also cognitive and emotional responses to the experience, encapsulated in the phrase embracing care. In this study, the carers described five positions within the spectrum of embracing care, and movements between them. This overall schema has not been previously described in the literature, although there are some relevant linkages.

Accepting embrace was primarily motivated by the care recipient’s needs (which they were unable or unwilling to manage themselves) and the expectation they would benefit from a technical health procedure. This could be an active choice by the carer or the naïve acceptance of medical advice. Carers might also feel compelled to accept embrace because of the financial consequences of not doing so (such as the costs of paying for alternative care). At the extreme of this position, some carers may over-embrace their role and seek to retain it even at the expense of the recipient’s best interests. Twigg and Atkin (1994) described this last type of caring relationship as “symbiotic” (p. 125), being “… situations where the carer derives positive benefits from their role, where they have no real wish for it to cease, and where their and the cared-for person’s needs are mutually reinforcing” (p. 126).
A study of seven patients with amyotrophic lateral sclerosis who used home ventilation and eight of their carers described three stages of ventilation use under the headings “Getting to know the ventilator” (nocturnal use), “Embracing the ventilator” (adding discretionary daytime use) and “Being on the ventilator on a 20-24-h basis” (essential life support) (Sundling, Ekman, Weinberg, & Klefbeck, 2009, p. 116). “Embracing the ventilator” has a different (temporal) sense to the concept of embracing care as developed in this thesis (varied responses to managing technical health procedures, without a linear time pattern); however, in both instances, there was an appreciation of the benefits of the technology.

In health professionals’ literature, an acceptance by carers of the role of managing a technical health procedure often seems to be assumed and the carer who accepts embrace will be ready to learn. However, willingness alone may not lead to the best care situation; health professionals in this study flagged the risks to the recipient of care driven by a financial imperative or over-embrace.

In contrast to accepting embrace, carers who resisted the role of managing technical health procedures had either not been persuaded that this was in the best interests of the recipient or accepted the need for the procedure but did not want to be the one to manage some or all of its care, particularly aspects which were distressing. Active or passive resistance by a potential carer was problematic for health professionals wanting to teach them; either the carer’s resistance had to be overcome or alternative care arranged.

The carer who accepted embrace largely deflected attention from their own needs to those of the recipient (although the needs of over-embracing carers may be apparent to others). Resistant carers, on the other hand, drew attention to their own needs. There was some overlap here with Twigg and Atkins’ (1994) “balancing/boundary setting mode” (p. 123) – “The essence of this lies in having an element of separation between the carer and the situation. Carers in this category placed greater value on their own autonomy, and made space for their own interests” (p. 123). Twigg and Atkins (1994) suggested this self-interest might take time to develop and could be associated with consciously adopting the title of carer as opposed to assuming the caring role was simply part of family relationships.

Continuing resistance to embrace depended on having the power to resist and the existence of an acceptable alternative. Otherwise, carers might reluctantly embrace the caring role. In this position, the carer’s needs were overridden in order to benefit the
recipient, yet continuing in this fashion is likely to be stressful for the carer and less than ideal for the recipient. Reluctant carers may develop sufficient strength to resist the continuing imposition of their role or they may move to accepting embrace if the benefits experienced by the recipient (or the advantages for their own care-work) overcome their doubts.

Burridge, Winch and Clavarino (2007) conducted a systematic review of the concept of reluctance to care, drawing on 17 studies (all but one of which involved care for adults, including those with chronic conditions, cancer and dementia). They defined two dimensions of reluctance: reluctance and resistance/refusal. Many of the indicators of reluctance were similar to those discussed in this study. They included demographic indicators such as gender role socialisation, the carer-recipient relationship and other life roles; physical indicators related to the characteristics of the recipient’s condition (duration, intensity, predictability) and the carer’s own health; psychological indicators under the headings of personal characteristics, perceptions of the role and motivations for it, perceptions of alternatives, and response to the role (including being overwhelmed by it); and finally, social indicators covering expectations of the patient and other family members, expectations of health professionals, where there were problems with preparation for caring, and limited access to resources for support (Burridge et al., 2007). Three important outcomes from reluctance to care were identified in this review: deterioration in the relationship between the carer and recipient, poorer quality of care and institutionalisation of the recipient (Burridge et al., 2007).

At another point on the spectrum of embracing care, carers relinquished embrace temporarily or permanently if their assistance was no longer required, and some chose to relinquish the role because they could no longer sustain it physically or psychologically. Relinquishment by a family carer may mean not only a change in care personnel but also in the location of care (for example, a move to residential care for an older person).

Enabling relinquishment again necessitates viewing carers’ needs as distinct from the recipients’ and of equal concern. At this point, carers may recognise and advocate for their own interests but if they cannot, there may be a place for health professionals encouraging and facilitating their relinquishment (Jayne Brown et al., 2001; Twigg & Atkin, 1994). While relinquishing care focuses on being relieved of the physical work of technical health care, other aspects of care, such as monitoring the...
quality of alternative care, advocacy, and providing emotional support to the recipient continue (Milligan, 2004; Nolan et al., 1996).

Caron and Bowers (2003) explored how carers decided to continue or relinquish their role in a grounded theory study involving 16 carers of older family members. They found two purposes for caregiving, the first being “interrelational” (protecting and maintaining the recipient’s sense of self as well as the relationship between carer and recipient) and the second “pragmatic” provision of good quality care (p. 1258). Decisions about getting assistance or relinquishing care were made by considering the purpose of care. In the interrelational phase, carers were more concerned with the recipient’s needs than their own and might view any proffered help as unnecessary or interfering with their relationship. However, if preserving the relationship became difficult and the focus shifted to practical care tasks, carers paid more attention to their own needs and were more willing to accept help from service providers. This particular pattern of relinquishment may be influenced by the study sample, ten of whom had cognitive impairments such as dementia. In contrast, in my own study, two mothers who had relinquished care of disabled children when they became young adults had done so because of their own health needs and the impact of caring on other family relationships, yet they were also intent on maintaining a close relationship with their child in residential care. Thus it was not so much a change in the purpose of care as physical factors and other family needs which drove relinquishment in these cases.

The final position in the spectrum of embracing care was being overwhelmed by the demands of caring, a state similar to that described as “engulfment mode” by Twigg and Atkin (1994, p. 122). While carers might have some choice about how much they invest themselves in their role and risk being overwhelmed, a very important factor in mitigating this was the degree of external support and alternatives they were offered. The value of professional and community support for carers has been highlighted previously (Given et al., 2001; Henry, 2008; Kirk & Glendinning, 2002; Sloper, 1999).

There are some similarities between the idea of embracing care and Roger’s theory about the diffusion of innovations (E. M. Rogers, 2003) which involves five stages: knowledge, persuasion, decision, implementation and confirmation. Carers accepting embrace were persuaded of the need for the procedure and willing to learn to manage it. Those resisting embrace were not persuaded, but might reluctantly embrace if they felt there was no alternative. Post hoc confirmation could move a reluctant carer
to accept embrace or conversely, lack of confirmation could shift carers to reluctance or relinquishing.

Movement around the spectrum of embrace was influenced by both changing circumstances (particularly the recipient’s health and external support) as well as by how carers evaluated the situation. In particular, an initial choice to embrace care might be made hurriedly, with little if any alternative, and limited understanding about what the reality of ongoing care will be like (Nolan et al., 1996). Therefore it is important to recognise carers may change their position on embracing care and to identify and respect their own needs alongside those of the care recipient, in the best interests of both parties.

Although context and external support are important, nevertheless, it is the carer’s individual experience which needs to be understood. As Jayne Brown, Nolan and Davies (2001) noted, “The pressures or difficulties of care can best be understood from a subjective rather than objective perspective. This means that the circumstances of care are less important than a carer’s perception of them” (p. 31).

**Implications**

- Technical health procedures need to be viewed in the context of any other care already being given (both to the recipient and any other family members) and the implications of adding additional responsibility considered.
- To embrace technical health procedures, carers need to clearly understand and accept the clinical need for and benefits of the procedure and be assured they will receive adequate training and ongoing support from the health system to manage. Where possible, preparation for a procedure is helpful.
- In encouraging embrace, health professionals may be walking a fine line between balancing the patient’s needs with coercing a carer. Care roles and responsibilities should be openly negotiated, rather than imposed through assumptions, expectations or a lack of alternatives.
- For carers managing a procedure for a family member, this is not only a technical process but one bound up with relationships and emotions. Health professionals can be aware of and support a carer’s emotional adjustment as well as their practical skills acquisition. This might involve some formal assessment and acknowledgement of the carers’ state of readiness to embrace care.
• Health professionals should not assume a carer’s willingness to embrace a procedure means they will continue to sustain this role indefinitely or can take on more in the future. Carers need to be offered opportunities to affirm their ability to carry on or be offered alternative support for themselves and their family member. Any additional care tasks should again be negotiated.
• Health professionals can help ensure carers have adequate support and opportunities for respite of an appropriate style and quality in order to prevent them being overwhelmed by their role. This means taking a preventative rather than ambulance-at-the-bottom-of-the-cliff approach.
• Relinquishing management of a technical health procedure may have mixed connotations for carers, depending on the circumstances in which it occurs. Even if they relinquish a hands-on role, carers continue to supervise and support the broader care of their family member and remain emotionally involved with them.

The context of managing technical health procedures at home

Throughout this thesis it has been emphasised that the focus was on technical health procedures being undertaken by family carers. The care recipients were loved family members – children, spouses, parents and grandparents. The relational nature of family care has been developed into an ethics of care theory, arising from feminist writers in the 1980s (Engster, 2007; Gilligan, 1982; Noddings, 2003). Ethics of care emphasises the interdependency of humans in relationship, rather than an idealised, independent individual; recognises the value of emotions; grounds morality in relationships rather than abstract principles; and attends to the traditionally private world of the family alongside public life (Held, 2006). If teaching and learning technical health procedures were viewed in this light, priority would be given to family relationships and the needs of both carers and recipients alongside the development of technical skills. Managing technical health procedures needs to be seen as more than technical competency; its implications for existing relationships also need to be considered and care taken to ensure these are strengthened rather than harmed.

Allied to the relational nature of family care are expectations (by family carers and recipients, health professionals and health services, and society generally) that family members should care for one another. An ethic of care “sees many of our responsibilities as not freely entered into but presented to us by the accidents of our
embeddedness in familial society and historical contexts” (Held, 2006, p. 14). That was apparent in this study when carers expressed their lack of choice about caring (albeit this did not mean they were unwilling to care). Health professionals attempted to offer families choices but recognised alternatives were often limited or undesirable to families. Whether or not acceptable options are available is therefore an important factor constraining choice.

Twigg and Atkin (1994) drew attention to the way normative social expectations about caring shape the views of both carers and service providers as to what carers should be expected to do and what services should be provided to assist them or care recipients. In particular, they asserted it is assumed that spouses and parents will naturally care for their partner or young child, while adult children could legitimately resist caring for their parents (particularly if they were not co-resident) and parents have reduced responsibility for their adult children (who are normally expected to develop towards independence) (Twigg & Atkin, 1994). In addition, gender, age, social class and ethnicity may shape expectations about who should care (Twigg & Atkin, 1994). In the present study, it was apparent that assumptions by both carers and health professionals influenced the degree of choice people perceived about their role, as did the availability or lack of alternative services. In particular, while there are residential care options for adults, this is no longer the case for children in New Zealand.

Two cross-sectional studies about carers’ choice have been undertaken in America with population-based samples, one at a state level (n=341 carers of people aged 18 and over) (Winter, Bouldin, & Andresen, 2010) and one with a national sample (n=1397 carers of adults aged 50 or older) (Schulz et al., 2012). About 45% in each study said they had not had a choice about becoming a carer. Both studies then used regression models and compared carers who said they had a choice with those who did not. Winter, Bouldin and Andresen (2010) reported carers without a choice were three times as likely to say they were stressed compared with those who felt they did have a choice. However, they noted stressed carers might be more likely to report they had not had a choice about their role; the temporal relationship could not be determined in this cross-sectional study. For their part, Schulz et al. (2012) found not having choice was significantly associated with physical strain, emotional stress and negative health impacts. These studies suggest improving choice is important for the health of carers.
The social norms and assumptions about the obligations of family members to care for one another raise issues of morality and social justice for individuals and family units, particularly in relationship to long-term technical health care (Arras, 1995; Arras & Dubler, 1994; Dow & McDonald, 2007; Levine, 1999a; Palm, 2013; World Health Organization, 2002). Lindemann (2007) has claimed,

The biomedical advances and socioeconomic forces that have given professional health care systems their current shape have put pressure on families to provide more care, of a more technical nature, than ever before. At the same time, changing social views as to how families may or must be configured, what the division of labour in the family is supposed to be and the extent to which families are expected to rely on professional health care all exert pressure in the opposite direction. The demands the two systems put on one another can give rise to considerable friction between them, particularly when there is a danger of exceeding the capacity of either to provide the needed care (p. 351).

Making technical health care more visible opens the opportunity for a societal conversation about service configurations and care expectations going forward. It also challenges us to review where primary responsibility for care lies – within the family or with society collectively – and the role of the state in its provision (Guberman & Maheu, 2002; McPherson, 2000).

Family care substitutes for services which might otherwise be provided publicly, hence saving the state and making a major social and economic contribution (Access Economics, 2005; van den Berg et al., 2004). Families may experience direct financial costs of caring as well as opportunity costs, alongside other physical, social and emotional costs, as also reflected in this study and many others (Goodhead & McDonald, 2007). The preponderance of female carers in this study, while it was not a representative sample, reflects the commonly-noted over-representation of female carers (Goodhead & McDonald, 2007).

Another contextual factor to consider about technical health care by families is its location in the home (and extending to community life). The private nature of the home means family care in general is hidden and working conditions are unregulated and largely unremunerated (Arno, Levine, & Memmott, 1999; Twigg, 1992). Thus, for example, family carers may be available for 24-hour care with limited respite, in contrast to the regulated hours and mandated breaks of health professionals’ work. Interestingly, the Funded Family Care policy that has recently been developed in New
Zealand limits the hours any family member can work to a maximum of 40 per week and allows for annual, sick and bereavement leave, framing this care as an employment relationship between family members (Ministry of Health, 2013). Unpaid New Zealand carers, however, are not subject to any such formal policies.

Another aspect of family care which has been hidden until recently is the work of young carers, but since the late 1980s, research has drawn attention to the contribution children make to care within families and the possible impacts of this role on the young carer (Aldridge & Becker, 1993; Dearden & Becker, 2000, 2002; Rose & Cohen, 2010). As with adults, family and cultural expectations along with a lack of alternatives influence the involvement of children in caring (Becker, Dearden, & Aldridge, 2000; McDonald, Cumming, & Dew, 2009; McDonald, Dew, & Cumming, 2010). While young caring was not a focus of this research, several of the family carers mentioned the involvement of their children in technical health care for a sibling, which is a significant responsibility for a young person.

**Implications**

- When family members are being asked to manage a technical health procedure, consideration should be given to the relationship between carers and recipients and how this may be affected or needs to be supported. Carers and care recipients have individual as well as intertwined needs. Supporting carers for their own sake is important and will also benefit the recipient (Hirst, 2004).

- Carers should make an informed choice to manage technical health procedures. This requires information about what caring will involve and how it may impact the carer. Choice also implies the existence of alternative care options. Given increasing demand for technical health care and the cost of replacing informal care with formal services, now is the time to open a societal conversation about what should be expected of families and what alternative services need to be provided in order to enhance choice.

- Allied to the above, we need to be explicit about the values that shape policy around family care for technical health procedures and expectations about who should care. This includes beliefs about the role of families and the state, and whether we see care as an individual or collective responsibility (Peter et al., 2007).
• Health professionals should be alert for the involvement of children in family care and consider their specific needs for support.

**Boundary issues between formal and informal care**

By definition, shifting the management of technical health procedures from professional control to lay carers transgresses traditional rules around who can be permitted to undertake these procedures. While scopes of practice and competence requirements are defined by professional bodies, no such regulations restrict family care. This raises the issues of risk and quality in family care.

A theoretical position expressed by some health professional participants in this study that carers could be taught anything was in practice delimited by carers’ willingness and health professionals’ gatekeeping for the sake of patient safety. Boundaries were set by organisational policy as well as assessment and negotiation at the individual level between health professionals and carers. While the degree of risk inherent in a procedure ostensibly set the boundary, it seems pragmatic issues were also important – for instance, the weekly changing of a central line dressing was mandated as a health professional task in one organisational policy because of the risk of septicaemia, yet home peritoneal dialysis is fully managed by patients and carers despite the risk of peritonitis. Are the risk and implications of peritonitis actually significantly lower than those of septicaemia or is it that the health system can sustain a weekly nurse visit to change a dressing but not four visits per day by a nurse to manage peritoneal dialysis at home? Therefore shifting these procedures to the community setting has come about through a combination of perceived benefits from home care as well as the financial implications for health services associated with increasing technical care and the pragmatic need to transfer some care to families if it is to happen at all (Marks, 1991; Teare, 2008; Wong, 1999).

Allied to managing risk was ensuring carers’ competence. In turn, the level of competence expected before carers could be entrusted with responsibility for managing at home depended on the degree of risk posed by a particular procedure. However, as studies monitoring carers’ practices at home have shown, continuing compliance with professional standards cannot be assumed, and where carers on-teach other family members, the competence of the latter may never be professionally assessed (S. Evans et al., 2007; S. Evans et al., 2012; S. Evans et al., 2011; S. Evans et al., 2010).
Professionally-set boundaries may be ignored by carers (which may or may not result in negative consequences for the recipient). In any case, different levels of risk may be appropriate in the home compared with a hospital setting. For example, the higher risk of infection in hospital means sterility is very important for some procedures while a lower standard of cleanliness may be safe at home.

Another issue to consider is where the boundaries of responsibility lie. Having trained a family carer and handed over day-to-day management to them, what continuing responsibility do health professionals have for supporting the carer and monitoring the quality of care? If the carer does something which negatively impacts the recipient, is the carer solely responsible? Alternatively, should we view such an incident as a systems issue and consider the adequacy of the training and ongoing support for the carer?

Finally, the management of technical health procedures by family members challenges professional codes of practice. For instance, the Medical Council of New Zealand Statement on Providing Care to Yourself and Those Close to You and the Nursing Council of New Zealand Guidelines: Professional Boundaries both state that caring for family or close friends should generally be avoided, except in emergencies or in small communities with limited access to other health care practitioners (Medical Council of New Zealand, 2013; Nursing Council of New Zealand, 2012). The purported reason is that objectivity is necessary for good patient care and a professional relationship. Yet family care by its very nature contravenes such boundaries of professionalism and dispassionate detachment.

The management of technical health procedures at home highlights their ambiguous position in the health system. This informal care has many of the characteristics of formal expertise, but operates in an unregulated and often hidden arena. In order for this care to be feasible (for the patient, the family and the health system), rules have to be broken or modified to suit individual circumstances. In these circumstances, guidelines rather than rigidly-applied boundaries are appropriate.

**Implications**

- Greater openness and clarity about the boundaries surrounding family management of technical health care would help to clarify professional and family responsibilities.
Issues around quality in family care require further consideration, particularly ongoing assessment of quality and issues of individual and systems responsibility.

Limitations of this study

This study has explored an important but largely overlooked aspect of family care, shedding new light on the experience of managing technical health procedures and how these are learnt. Some limitations of the research must also be acknowledged. In their interviews, family carers were giving retrospective accounts of events, while health professionals described their usual practices. Inevitably, participants will have highlighted what seemed most important to them, yet may also have forgotten events or details or chosen not to share incidents which might portray them in a bad light. As human interactions, the interviews were co-created by the participants and myself, and my choices about what to ask and follow up (or not), along with participants’ choices about their responses took each conversation in particular directions while others were missed. In addition, time constraints and one-off interviews sometimes precluded obtaining fuller detail.

From a constructivist grounded theory perspective, any study is interpretive. My positioning and influence on the study have been discussed with my supervisors and mentor as the study progressed and outlined with the methodology. While wayfinding is my interpretation of the participants’ accounts, it is well-grounded in the data and thus provides a reasonable explanation of what was happening.

The ability to control sampling in this study was limited by recruitment strategies that relied on the goodwill of intermediaries informing potential participants about the study or advertising it through their networks. Theoretical sampling in its classical form was therefore not possible. However, emerging theoretical concepts were tested in succeeding interviews and continued sampling eventually provided all the variations I sought (such as early and later experiences of caring, and all the predicted positions of embracing care). The final sample had a preponderance of parent-carers over those caring for an adult family member; unfortunately there are no data as to the actual proportions of these two groups within the total carer population of those who manage technical health procedures. As has been noted, the alternatives to family care, and therefore the degree of choice in caring, may differ between these groups, as may the likely duration of care. However, the learning process and embracing care
developed from and were applicable to both groups. Ideally, recruiting some further Māori and Pacific Island participants would have been desirable to ensure the theory is also appropriate for that population, but the data from the one Māori participant and the others of non-New Zealand European ethnicity again fitted the same patterns of learning and experience. As with any grounded theory, this one remains open to modification with further data.

**Directions for further research**

There are a number of ways that this study and the theory of wayfinding could be built on. This research was situated in New Zealand, which has its own cultural context and health system framing the way teaching and learning took place. Undertaking similar research in other environments would confirm or refine the theory.

Some of the weakness of retrospective accounts could be overcome if a longitudinal approach were taken, interviewing each carer several times to follow their learning process. This would enable more contemporaneous data collection and the ability to gather additional detail about each stage of learning. However, this would be more onerous for participants and recruitment might be more difficult. Ideally, data would be further enhanced through observation of teaching times with health professionals and day-to-day management at home, but this would create significant ethical concerns, including the observation of some intimate procedures (such as intermittent urinary catheterisation). Observation would also require the consent of the care recipient, some of whom would be considered vulnerable. Furthermore, in the case of children, some would require the consent of the same parent who would also be participating, creating a conflict of interest. Both repeated interviews and observation would add significantly more researcher time and cost too.

Another avenue for future research would be to extend the reach of this theory. The focus on learning by family carers could be broadened to include other people who learn to manage technical health procedures, such as secondary family members (including children), school staff, respite carers and residential care workers (Smith, Williams, & Gibbin, 2003; Townsley & Robinson, 1999). This would move the learning beyond the context of family relationships and could raise other issues such as employer-employee relationships, workplace health and safety issues, and relationships between paid carers and families (Maddox & Pontin, 2013).
Another group that could be incorporated are patients themselves. This study has presented the learning experience from the perspective of family carers, and while the care recipient was frequently referred to in interviews, their own voice has not been heard – what is it like to receive this kind of care from a family member? For those who go on to learn to self-manage (as some children would), what is the learning process like for them?

A further way to extend the scope of the theory would be to widen the learning focus from the range of technical health procedures included in this study to other care procedures and roles such as giving physiotherapy or behavioural interventions. These would provide additional material for comparison and help to delineate the bounds of technical health care.

Finally, little is known about the numbers of technical health procedures being managed in the community and whether these are increasing or becoming more complex. Better data, such as District Health Board or national registers of procedures in New Zealand would inform the development of teaching and support programmes.

Conclusion

In her foreword to the current New Zealand Carers’ Strategy Action Plan (Ministry of Social Development, 2014), the Honourable Jo Goodhew, Minister for Senior Citizens, said that in the face of an ageing population, with increasing demand for community care and therefore family support, “Now more than ever we need to acknowledge and support this diverse, skilled and generous group we call ‘carers’” (p. 2).

This thesis has drawn attention to the work of a particular group of carers who are seldom recognised even in the caregiving literature, namely those who manage technical health procedures. The grounded theory of wayfinding developed through this research provides a framework for understanding the learning journey and experiences of these carers, shaped by the social context in which they work. The research challenges health professionals and health services to recognise these carers, consider their needs and think about how best to support them in the vital contribution they make to patient care.
The last word comes from a carer, who said, “I hope that as a result of your PhD families and professionals will be better able to work together and understand each other’s point of view.”
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common ground among families, health professionals, and policy makers (pp. 87-102). Baltimore: Johns Hopkins University Press.


Appendix A: Ethical approval, family carer interviews

26 August 2011
Amended 27 August 2011
Amended 5 September 2011
Amended 7 September 2011
Amended 23 November 2011

Ms Janet McDonald
PhD Student, University of Otago (Wellington)
Rehabilitation Teaching & Research Unit, Department of Medicine
PO Box 7343
Wellington 6242

Dear Ms McDonald -

Ethics ref: MEC/11/EXP/076 (please quote in all correspondence)
Study title: Family carers doing technical health procedures at home - their learning experiences.
Investigators: Ms Janet McDonald

This expedited study was given ethical approval by the Chairperson of the Multi-region Ethics Committee on 26th August 2011.

Approved Documents

- Expedited Review of Observational Studies (for the above study)
- Study protocol, version 1, dated 18 August 2011
- Participant Information Sheet, version 2, dated 5 September 2011
- Consent Form, version 2, dated 5 September 2011
- Interview guide, version 1, dated 18 August 2011
- Demographic Data Collection Tool, version 1, dated 18 August 2011
- Confidentiality agreement for typists

Matters of comment, information or advice

The Committee also forwards the following comments, information and advice, which do not affect the application’s ethical approval status.

- The Chair would like to note some minor points which do not stop the study from proceeding. The first relates to Section 5(c) of the application where the “No” box has been marked where the application asks if the study is part of an educational qualification, however the text says it is part of a PhD. Only a minor issue.
- The Chair has also noted that the investigator will give participants a koha at the end of the study. The Chair supports this however, would advise the investigator to exercise caution so that the koha doesn’t appear like a financial inducement. The Chair has suggested that participants not be told about the koha until after their interviews.
This approval is valid until **26th August 2013**, provided that Annual Progress Reports are submitted (see below).

**Annual Progress Reports and Final Reports**

The first Annual Progress Report for this study is due on the **26th August 2012**. The Annual Report Form is available at [www.ethicscommittees.health.govt.nz](http://www.ethicscommittees.health.govt.nz). Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at [www.ethicscommittees.health.govt.nz](http://www.ethicscommittees.health.govt.nz).

We wish you all the best with your study.

Please do not hesitate to contact me should you have any queries.

Yours sincerely

Laura Jayne Burlison  
Administrator  
Multi-Region Ethics Committee  
Email: Multiregion_ethicscommittee@MOH.govt.nz
Appendix B: Ethical approval, health professional interviews

2 April 2012

Ms Janet McDonald
University of Otago
Rehabilitation Teaching & Research Unit
P O Box 7343
Wellington 6242

Dear Ms McDonald

Ethics ref: MEC/12/EXP/047 (please quote in all correspondence)
Study title: Family carers doing technical health procedures at home - their learning and experiences

This study was given expedited ethical approval by the Chair of the Multi-region Ethics Committee on 2 April 2012.

Approved Documents
— Expedited Review of Observational Studies Application Form signed and dated 22 March 2012 by Janet McDonald
— Study Protocol, Phase 2, dated 22 March 2012
— Participant Information Sheet for professionals, Phase 2, dated 22 March 2012
— Consent Form for professionals, Phase 2, dated 22 March 2012
— Interview Schedule, Version 1, dated 22 March 2012
— Demographic Data Collection Tool, Version 1, dated 22 March 2012

This approval is valid until 31 January 2016, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations
All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:
— the researcher responsible for the conduct of the study at a study site
— the addition of an extra study site
— the design or duration of the study
— the method of recruitment
— information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports
The first Annual Progress Report for this study is due to the Committee by 2 April 2013. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz.
Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at [www.ethicscommittees.health.govt.nz](http://www.ethicscommittees.health.govt.nz).

**Statement of compliance**
The committee is constituted in accordance with its Terms of Reference. It complies with the *Operational Standard for Ethics Committees* and the principles of international good clinical practice.

The committee is approved by the Health Research Council’s Ethics Committee for the purposes of section 25(1)(c) of the [Health Research Council Act 1990](http://www.govt.nz).

We wish you all the best with your study.

Yours sincerely

Emma Phelan
Administrator
Multi-region Ethics Committee
Family carers doing technical health procedures at home –
their learning and experiences.

Participant Information Sheet

An invitation
You are invited to take part in a study about family carers who are doing technical health procedures at home. Family carers are people who help or support a family member who is ill, disabled or frail elderly. Technical health procedures include such things as renal dialysis; urinary catheterisation; intravenous therapy; injections; caring for a bowel or bladder stoma/ostomy; enteral or parenteral nutrition (e.g. PEG feeding or naso-gastric tube feeding); managing a tracheostomy, ventilator or oxygen therapy; enemas or bowel washouts; wound care and dressings; and some physiotherapy procedures.

Your participation in this study would involve one interview about how you learnt to do a technical health procedure and your experiences of managing this procedure at home. This would take approximately 60-90 minutes of your time.

Participating in this study
This study is about family carers who do some sort of technical health procedure such as those listed above.

If you are interested in taking part in this study, please read the rest of this information sheet. You may take as much time as you like to consider whether or not to take part. If you do agree to take part, you remain free to withdraw from the study at any time without having to give a reason.

Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study. Whether or not you take part will not affect any health or social services you or a family member receive.

Who is doing this study?
This study is being done by Janet McDonald who is a PhD student at the University of Otago (Wellington). Janet has been doing health services research part-time for the last 7 years and is also a family carer herself. Her contact details and those of her supervisors are provided at the end of this information sheet.
What is the purpose of this research?

Family carers manage a variety of technical health procedures at home, but we don’t know much about what it’s like for (largely) ‘lay’ people to take on this kind of role, or how professionals like nurses teach and support carers. The purpose of this research is to find out about carers’ experiences and learning in order to inform professionals about how they can best support family carers in this situation. The study will also be written up for Janet’s PhD and the findings may be presented at conferences or in journal articles.

Who can take part in the study?

You can choose to take part in this study if:

- You are a family carer who does some kind of technical health care, and
- You are 16 years of age or older, and
- You can communicate verbally in English.

This study does NOT include people who manage their own care or people who do technical health care as part of their work (such as teacher aides or health care assistants).

What happens if I do decide to take part?

If you are interested, please contact Janet McDonald (details at end) who will discuss the study with you. If you are willing to take part, she will arrange a convenient time and place to interview you. This may be in your home or at another suitable location. If you agree, she will record the interview so that she can concentrate on what you are saying and review the information afterwards and not miss any details. However, if you prefer not to have the interview recorded, she will ask your permission to write notes.

If you wish, you can choose to have a support person with you during the interview, but this should not be the person you care for, in order to protect their privacy and yours.

What will happen with the information from your interview?

Janet will type up the recording of your interview, with all personally identifying information removed (such as names of people, places or organisations). She will then compare your information with what other participants say and analyse the experiences and ways that family carers learn to do technical health procedures.

If you wish, she will send you a typed copy of your interview shortly afterwards. Later, she will send a summary of findings from this study if you want (expected to be by December 2013).

The interview recording and all other information that you provide will remain strictly confidential. They will be securely stored on the researcher’s work computer (password protected) or in a locked filing cabinet. Only Janet and her supervisors will have access to this information. Electronic audio files and transcripts will be retained for 10 years in secure university storage; after this, they will be destroyed.
No material that could personally identify you will be used in any reports from this study.

**How will the study affect me?**

Participating in this study will take 1 - 1½ hours of your time and require you to talk about your experience of caring, including doing any technical health procedure/s. There are no direct benefits to you from taking part in this study, but some people may appreciate an opportunity to talk about their experiences and contribute to research about family carers.

It is possible you may find talking about some aspect of your experience is upsetting. You do not have to answer all the questions and you may stop the interview at any time. You can choose not to participate further or to withdraw from the study at any point.

If you disclose any information that suggests either you or someone else is at risk of harm, the researcher will notify your GP or another appropriate health service. Where possible, she will discuss this with you first.

**Your rights**

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate: Freephone 0800 555 050 or email: advocacy@hdc.org.nz

**Funding and Ethical approval**

Janet has received a Health Research Council of New Zealand PhD scholarship to undertake this research.

This study has received ethical approval from the Multi-region Ethics Committee. Ethics reference number: MEC/11/EXP/076

**For more information**

If you would like more information about this study or are considering taking part, please feel free to contact:

**Lead researcher:** Janet McDonald

**Address:** Department of Medicine, University of Otago Wellington, PO Box 7343, Wellington 6242

**Phone:** 04 806 1032

**Email:** mcdja111@student.otago.ac.nz

OR either of her supervisors:

Dr William Levack

**Phone:** 04 385 5541 x6564

**Email:** william.levack@otago.ac.nz

Dr Sally Keeling

**Phone:** 03 337 7932

**Email:** sally.keeling@otago.ac.nz

Thank you for reading about this study.

Please keep this information sheet for your reference
Family carers doing technical health procedures at home – their learning and experiences.

Phase 2: Interviews with professionals

Participant Information Sheet

About this study

Family carers help or support a family member who is ill, disabled or frail elderly. Their caring commonly involves personal care or household tasks, but can also include managing technical health procedures such as renal dialysis; urinary catheterisation; intravenous therapy; injections; caring for a bowel or bladder stoma/ostomy; enteral or parenteral nutrition (e.g. PEG feeding or naso-gastric tube feeding); managing a tracheostomy, ventilator or oxygen therapy; enemas or bowel washouts; wound care and dressings; and some physiotherapy procedures.

Although family carers may manage such procedures at home, we don’t know much about what it’s like for (largely) ‘lay’ people to take on this kind of role, or how professionals like nurses teach and support carers. In the first phase of this study, family carers are being interviewed about their learning and experiences of managing technical health procedures. The second phase of the study involves interviews with professionals to gain their perspective about how they teach carers.

An invitation

Does your role include teaching family carers how to manage technical health procedures such as those above? If so, you are invited to take part in this study.

Your participation would involve one interview about how you teach and support carers. You may choose to be interviewed individually (1 hour) or in a group of 2-4 professionals (1.5 hours).

Participating in this study

If you are interested in taking part in this study, please read the rest of this information sheet. You may take as much time as you like to consider whether or not to take part. Your participation in this study is entirely voluntary. If you do
agree to take part, you remain free to withdraw from the study at any time without having to give a reason.

Who is doing this study?

This study is being done by Janet McDonald who is a PhD student at the University of Otago (Wellington). Janet has been doing health services research part-time for the last 7 years and is also a family carer herself. Her contact details and those of her supervisors are provided at the end of this information sheet.

What is the purpose of this research?

The purpose of this research is to find out about carers’ experiences and learning in order to inform professionals about how they can best support family carers in this situation. The study will also be written up for Janet’s PhD and the findings may be presented at conferences or in journal articles.

Who can take part in the study?

You can choose to take part in this study if your professional role includes teaching family carers how to manage technical health procedures. Your role may also include teaching patients self-management, or teaching non-family members (such as teacher aides or health care assistants), but the focus of this study is on teaching family carers.

What happens if I do decide to take part?

If you are interested, please contact Janet McDonald (details at end) who will discuss the study with you. If you are willing to take part, she will arrange a convenient time and place to interview you. If you agree, she will record the interview so that she can concentrate on what you are saying and review the information afterwards and not miss any details. However, if you prefer not to have the interview recorded, she will ask your permission to write notes.

What will happen with the information from your interview?

Janet will type up the recording of your interview, with all personally identifying information removed (such as names of people, places or organisations). She will then compare your information with what other participants say and analyse the experiences and ways that family carers learn to do technical health procedures.

If you wish, she will send you a typed copy of your interview shortly afterwards. Later, she will send a summary of findings from this study if you want (expected to be by December 2013).

The interview recording and all other information that you provide will remain strictly confidential. They will be securely stored on the researcher’s work computer (password protected) or in a locked filing cabinet. Only Janet and her supervisors will have access to this information. Electronic audio files and transcripts will be retained for 10 years in secure university storage; after this, they will be destroyed.
No material that could personally identify you will be used in any reports from this study.

**How will the study affect me?**

Participating in this study will take 1 - 1½ hours of your time and require you to talk about your experience of teaching technical health procedures. There are no direct benefits to you from taking part in this study, but you will contribute to knowledge about teaching family carers about technical health procedures which will be useful for professional practice.

**Your rights**

You do not have to answer all the questions and you may stop the interview at any time. You can choose not to participate further or to withdraw from the study at any point.

**Funding and Ethical approval**

Janet has received a Health Research Council of New Zealand PhD scholarship to undertake this research.

This study has received ethical approval from the Multi-region Ethics Committee. Ethics reference number: MEC/12/EXP/047

**For more information**

If you would like more information about this study or are considering taking part, please feel free to contact:

**Lead researcher:** Janet McDonald
**Address:** Department of Medicine, University of Otago Wellington, PO Box 7343, Wellington 6242
**Phone:** 04 806 1032
**Email:** mcdja111@student.otago.ac.nz

OR either of her supervisors:

Dr William Levack
**Phone:** 04 385 5541 x6564
**Email:** william.levack@otago.ac.nz

Dr Sally Keeling
**Phone:** 03 337 7932
**Email:** sally.keeling@otago.ac.nz

**Thank you for reading about this study.**

*Please keep this information sheet for your reference.*
Appendix E: Consent form, family carers

Family carers doing technical health procedures at home – their learning and experiences.

CONSENT FORM – Participant interviews

1. I have read and I understand the Information Sheet about family carers doing technical health procedures at home (Version 2, 5/9/11). Yes □  
2. I have had time to consider whether to take part in the study. I have been able to discuss this study and have any questions answered before I take part. I have had the opportunity to use family/whānau support or a friend if I wished to help me ask questions and understand the study. Yes □  
3. I understand that taking part in this study is voluntary (my choice), and that I may choose not to answer some questions or withdraw from the study at any time and this will in no way affect any health or social services I or a family member receive. Yes □  
4. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study. Yes □  
5. I understand that I can choose to have a support person (other than the person I care for) present during my interview. Yes □  
6. I know who to contact if I have any questions about the study. Yes □  
7. I understand that my GP or an emergency health service will be notified if I disclose any information that suggests that either I or someone else is at risk of harm. Where possible, the researcher will discuss this with me first. Yes □  
8. I consent to my interview being recorded. Yes □ No □  
9. I wish to receive a copy of my typed interview. Yes □ No □  
10. I wish to receive a summary of the findings from this study (expected to be by December 2013). Yes □ No □

I …………………………………………………………hereby consent to take part in this research.

Signature ……………………………………. Date …………………

Project explained by Janet McDonald who is conducting the research.

Researcher’s contact phone number: (04) 806-1032

Signature…………………………………………………… Date …………………

This study has received ethical approval from the Multi-region Ethics Committee. Ethics reference number: MEC/11/EXP/076

Family carers doing technical health procedures at home – their learning and experiences
Consent form for participants, version 2, 19/10/11
Appendix F: Consent form, health professionals

Family carers doing technical health procedures at home – their learning and experiences.
CONSENT FORM – Professional participants

1. I have read and I understand the information sheet for professionals about family carers doing technical health procedures at home (Version 1, 22/3/12).

2. I have had time to consider whether to take part in the study. I have been able to discuss this study and have any questions answered before I take part.

3. I understand that taking part in this study is voluntary, and that I may choose not to answer some questions or withdraw from the study at any time.

4. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

5. I know who to contact if I have any questions about the study.

6. I consent to my interview being recorded.

7. I wish to receive a copy of my typed interview.

8. I wish to receive a summary of the findings from this study (expected to be by December 2013). If yes, please provide a contact address:

I ………………………………………………………..hereby consent to take part in this research.

Signature ................................. Date ......................

Project explained by Janet McDonald who is conducting the research.

Researcher’s contact phone number: (04) 806-1032

Signature…………………………………………... Date ..................

This study has received ethical approval from the Multi-region Ethics Committee. Ethics reference number: MEC/12/EXP/047
Appendix G: Demographic data collection form, family carers

Demographic Data Collection Tool

Family carers doing technical health procedures at home – their learning and experiences

1. Participant ID ............................

2. Gender ............................

3. Age ............................

4. The person you care for is your (mother, daughter etc).............................................
   Their age ....................
   How long have you been caring for this person? ...................................................

5. Other members of this household and their relationships:
   ........................................................................................................................................
   ........................................................................................................................................
   ........................................................................................................................................
   ........................................................................................................................................
   ........................................................................................................................................
   ........................................................................................................................................

6. Which ethnic group do you belong to?
   Mark the space or spaces which apply to you.
   □ New Zealand European
   □ Māori
   □ Samoan
   □ Cook Island Maori
   □ Tongan
   □ Niuean
   □ Chinese
   □ Indian
   □ Other (please state:..................................................)
Appendix H: Demographic data collection form, health professionals

Demographic Data Collection Tool

Professionals who teach family carers to do technical health procedures at home

1. Participant ID ...........................

2. Gender .............................

3. Age .................................

4. Which ethnic group do you belong to?
   Mark the space or spaces which apply to you.
   □ New Zealand European
   □ Māori
   □ Samoan
   □ Cook Island Maori
   □ Tongan
   □ Niuean
   □ Chinese
   □ Indian
   □ Other (please state: ..............................................................)

5. What is your current professional role?
   ..........................................................................................................................

6. What is your professional qualification? ..............................
   What year did you graduate? .............

7. Please list any post-graduate qualifications you hold:
   ..........................................................................................................................
   ..........................................................................................................................
   ..........................................................................................................................
Appendix I: Interview guide, family carers

Family carers doing technical health procedures at home – their learning and experiences.

Interview Guide

Note: Additional questions that were added as the study proceeded are italicised.

<table>
<thead>
<tr>
<th>Question</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me about the procedure/s you do with your (mother/daughter etc)</td>
<td>Equipment – explain its use; where kept; disposal</td>
</tr>
<tr>
<td>2. How did you come to be involved with doing this?</td>
<td>Choice/obligation/expectations</td>
</tr>
<tr>
<td></td>
<td>Are other family members also involved?</td>
</tr>
<tr>
<td>3. When did you start doing (procedure)?</td>
<td>Who did the teaching? (professionals; others e.g. another family member; other carers) <em>Use of internet</em></td>
</tr>
<tr>
<td></td>
<td>What was taught? (e.g. technical skills; decisionmaking; troubleshooting)</td>
</tr>
<tr>
<td></td>
<td>How was the teaching done? (e.g. demonstration, written materials, DVD)</td>
</tr>
<tr>
<td></td>
<td>When did teaching occur? (e.g. before or after hospital discharge); <em>preparation beforehand</em></td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Where did teaching take place? (e.g. hospital, home)</td>
<td>How long did the teaching take?</td>
</tr>
<tr>
<td>Was there any assessment of your learning/competence?</td>
<td>What was most helpful in the teaching process?</td>
</tr>
<tr>
<td>Any difficulties with the teaching process?</td>
<td>Previous education and employment</td>
</tr>
<tr>
<td>4.. What’s it been like for you to manage (procedure) at home?</td>
<td>Taking responsibility; initial anxiety?</td>
</tr>
<tr>
<td>Tell me about your relationship with professionals who also care for</td>
<td>Any worry about causing pain or harm to their family member</td>
</tr>
<tr>
<td>(family member).</td>
<td>Support (professional and other)</td>
</tr>
<tr>
<td></td>
<td>Any changes over time</td>
</tr>
<tr>
<td></td>
<td>Any problems and how these have been dealt with</td>
</tr>
<tr>
<td></td>
<td>How do you view the technology/procedure?</td>
</tr>
<tr>
<td></td>
<td>Advantages/disadvantages of the technology/procedure?</td>
</tr>
<tr>
<td></td>
<td>Ordinary/extraordinary care boundaries?</td>
</tr>
<tr>
<td></td>
<td>Becoming expert</td>
</tr>
</tbody>
</table>

Family carers doing technical health procedures at home – their learning and experiences
Interview schedule, version 1, 18/8/11
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>4a. How does (procedure) impact your daily life?</td>
<td>How is it fitted into daily routines?</td>
</tr>
<tr>
<td>How do you view managing (procedure) in relation to all of your</td>
<td>How much time does it take?</td>
</tr>
<tr>
<td>caring (e.g. small/large component)?</td>
<td>Monitoring of equipment and care needs</td>
</tr>
<tr>
<td></td>
<td>Adapting to life with a technical health procedure</td>
</tr>
<tr>
<td>5. What’s helped you the most?</td>
<td>What would you tell another carer about to start managing (procedure)?</td>
</tr>
<tr>
<td>Is there anything that would have improved the teaching you received or</td>
<td>What’s most important for health professionals to tell you and to know</td>
</tr>
<tr>
<td>any other support you’d like to have?</td>
<td>about what managing (procedure) is like?</td>
</tr>
<tr>
<td>6. Are there any other people who help with your (daughter’s) (procedure)?</td>
<td>Who? (other family members; respite carers; teacher aides etc)</td>
</tr>
<tr>
<td>If so, how did they learn what to do?</td>
<td>If you did the teaching, how did you go about it, and what was it like</td>
</tr>
<tr>
<td></td>
<td>to be the trainer?</td>
</tr>
<tr>
<td>6b. Their thoughts on the ideas of becoming expert and embracing care.</td>
<td></td>
</tr>
<tr>
<td>7. Is there anything else we haven’t covered that you think is important?</td>
<td>What do you think will happen with your involvement with caring in the future?</td>
</tr>
</tbody>
</table>

Thank you for your time and input.
### Appendix J: Interview guide, health professionals

**Family carers doing technical health procedures at home – their learning and experiences.**

**Professionals’ Interview Guide**

*Note: Additional questions that were added as the study proceeded are italicised.*

<table>
<thead>
<tr>
<th>Question</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong></td>
<td></td>
</tr>
<tr>
<td>a) What is your professional role?</td>
<td>How much involvement do you generally have with family members (as opposed to patients themselves)?</td>
</tr>
<tr>
<td>b) Have you taught procedures to family carers?</td>
<td></td>
</tr>
<tr>
<td>c) What sort of procedures do you teach family carers?</td>
<td></td>
</tr>
<tr>
<td>d) How long have you been doing this for?</td>
<td></td>
</tr>
<tr>
<td><strong>2.</strong></td>
<td></td>
</tr>
<tr>
<td>a) What leads to family members taking on the management of technical health procedures?</td>
<td>How much choice is there for family members as to whether they will take on technical health care?</td>
</tr>
<tr>
<td>b) What motivates carers to learn to manage a procedure?</td>
<td>What alternatives are available if no family members are able to take on this care?</td>
</tr>
<tr>
<td>c) Do you have a process to assess whether a carer is suitable to learn a technical health procedure?</td>
<td>Is there anyone they think can’t or shouldn’t learn? Why?</td>
</tr>
<tr>
<td>d) How do you assess when a carer is ready and willing to take on learning a procedure?</td>
<td><em>Assessment of prior knowledge/skills?</em></td>
</tr>
</tbody>
</table>

---

Family carers doing technical health procedures at home – their learning and experiences  
Professionals’ interview schedule, version 1, 22/3/12
3. a) Tell me about the process of teaching a procedure.  
    Who do they teach? e.g. 1 or more family members; individual or group teaching  
    b) What training have you received about how to teach carers to do procedures?  
    Any nursing/teaching theories they use?  
    Who does the teaching? e.g. 1 or several professionals  
    When does teaching begin? e.g. before or after surgery  
    Where does the teaching take place? e.g. in hospital, at home;  
    Any differences between doing the procedure in the hospital or home setting?  
    What do you teach? e.g. procedural steps, decision making, monitoring, problem solving, infection control, disposal of sharps and other equipment  
    What teaching methods do you use? e.g. ‘show and tell’, mannequins, written materials, DVD, internet resources, other carers?  
    How is teaching documented?  
    Could I have a copy of any resources?  

4. How do you take into account carers' cultural needs in the learning process?  
   Do you have resources in other languages?  

5. How long would it generally take to teach a procedure?  
   How many teaching sessions?  

6. a) How do you assess when a carer is competent to manage the procedure safely on their own?  
   Informally/clinical judgement?  
   b) Do you have any follow-up or ongoing assessment once a person is managing on their own?  
   Any formal assessment?  
   c) What ongoing support if available to carers once they are managing on their own?  
   Including after hours or emergency situations. Links with primary health care.  
   d) Who is responsible for safety and quality of care once family carers are managing procedures at home?  
   Ongoing professional responsibility/liability? Any concerns about safety and quality of procedures being done by carers at home?  
   e) Do you have any concerns about risk? To whom?  
   Have you ever been surprised by something carers were doing at home?  
   f) When is the point of discharge from a service?
7. a) What have you observed about what the process of learning is like for carers?  
    b) Is there anything that seems to make it easier or harder for carers to learn?  
    c) Are there any common problems that carers seem to experience and how do they manage these?  

    e.g. initial anxiety, becoming confident and expert, modifying procedures

8. Have you known any carers who have been unable to continue managing a procedure at home?  
    Can you talk about what happened?  
    Can you identify what caused this issue?  
    What were the consequences for the person they cared for?

9. Are there any procedures you think carers should not be allowed or expected to manage at home? Why or why not?  
    Rheumatic fever injections?  
    Drawing up medication?

10. Do you have any comments about trends or changes in family carers taking on technical health procedures at home?

11. The focus of this research is family carers undertaking technical health procedures. However, do you have any comments about similarities or differences between teaching patients self-management, or teaching other non-family carers (such as teacher aides or health care assistants)?

11b. Their thoughts on the ideas of becoming expert and embracing care.

12. Is there anything else we haven’t covered that you think is important?  
    Respite? Equipment supplies (cost, access, storage)? Transfers across DHBs?

Thank you for your time and input.
Appendix K: Conference presentations arising from this thesis

1. Otago University Division of Health Sciences Research Forum, Dunedin, 17-18 September, 2012: Poster abstract

Title: Embracing Care: Family Carers Managing ‘Technical Health Procedures’ at Home

Author: Janet McDonald

Abstract

Background
Advances in medical care and technology, population ageing, policy shifts and family preferences for community over institutional settings are contributing to increased care at home, much done by family carers. Beyond housework, personal care or advocacy, some carers take responsibility for ‘technical health procedures’ ranging from changing wound dressings to managing a tracheostomy. We know little about what it’s like for (largely) ‘lay’ people to take on such roles, or how professionals like nurses teach and support carers.

Research questions
What are the experiences of family carers who undertake ‘technical health procedures’ at home?
How do professionals teach family members the necessary skills for such procedures, and what is the process of learning from carers’ perspectives?

Methodology
This exploratory research suits a qualitative approach. Grounded theory methodology was chosen because of its focus on generating theory about processes (here, learning ‘technical health procedures’).
Carers managing a variety of technical health procedures are currently being interviewed. The next research phase will involve interviewing professionals who teach carers.

Early Findings
Grounded theory involves an iterative process of data collection, coding and analysis until saturation is reached. Analysis is still in an early stage (12 carer interviews), but one notable finding is the concept of ‘embracing the technology’. Carers who embrace the technology because of its perceived benefits may be more willing to take on this care, in contrast to those who ‘resist embrace’. Positions are not fixed, and carers may move from reluctant to willing embrace, or choose to relinquish embrace.
Title: Considering the contribution to the health system of family carers who manage ‘technical health procedures’ at home

Authors: Janet McDonald, William Levack, Sally Keeling

Abstract
Objectives
Advances in medical care and technology, population ageing, policy shifts and family preferences for community over institutional settings are contributing to increased care at home, much done by family carers. Beyond housework, personal care and/or advocacy, some carers take responsibility for ‘technical health procedures’ ranging from changing wound dressings to managing a tracheostomy.
The objectives of this research are to describe and develop theory about the learning process of family carers and their experience of managing technical health procedures at home.

Methods
Grounded theory methodology with data drawn from interviews with 26 family carers and 10 health professionals.

Lessons Learned
With a continuing emphasis on community care, family carers are an essential but often hidden workforce, supplementing and substituting, unpaid, for professional services.
The ‘choice’ to care is often constrained by societal, family and health system expectations and limited alternative professional services.
Family carers may manage one or more procedures, with varied training and support. Over time, they can develop expertise with complex care. Their relationship with professionals may evolve from that of learner-teacher to one of partnership.
The boundaries between carer and professional roles are ill-defined.

Implications
This presentation will provide a framework for considering the role of family carers who provide technical health care at home and the training and support they need from health services.
Title: Embracing care: The experience of family carers managing technical health procedures at home

Authors: Janet McDonald, William Levack, Sally Keeling, Eileen McKinlay

Abstract
Advances in medical care and technology, population ageing, policy shifts towards community care and family preferences for home over institutional settings are contributing to increased demands on family carers. Beyond housework or personal care, some carers take responsibility for ‘technical health procedures’ ranging from changing wound dressings to managing a tracheostomy. There is limited research about carers’ experiences with such roles or how professionals teach and support them.

The objectives of this research were to develop theory about how families learn to undertake technical health procedures and their experiences of managing these procedures at home. Grounded theory methodology was used with data drawn from interviews with 26 family carers caring for their child (20), partner (3), parent or grandparent (3). Technical procedures included nasogastric or gastric feeding, intravenous medication, tracheostomy management and peritoneal dialysis. In addition, 15 health professionals involved with teaching family carers were interviewed.

An overall theory of ‘wayfinding’ has been developed, comprising two major processes: a learning process (moving from initial training to novice caring to becoming an expert carer) and ‘embracing care’ which describes the way family carers experience and respond to taking on the role of managing technical health procedures.

This presentation will focus on the spectrum of embracing care (accepting embrace, resisting embrace, reluctant embrace, relinquishing embrace and being overwhelmed by the caring role) and describe patterns of movement between these positions. It will also consider the social and health services contexts in which embracing care occurs and the implications for health professional practice.
Appendix L: Summary of findings for participants

Family carers doing ‘technical health procedures’ at home – their learning and experiences.
Summary of research findings prepared by Janet McDonald, November 2013

Introduction

This is a summary of the findings from my study about family carers who manage ‘technical health procedures’ at home. The focus of the study has been to find out about the experiences of those who do this kind of care, and how they learn to do these procedures. To do this, I interviewed family carers first, and then a range of the health professionals who teach carers. Initially I looked at the information from each group separately, but have now integrated the material from both groups into these overall findings.

Although these findings focus on managing a technical health procedure, I am aware this was only part of the care that was going on in the families I met. Although some people said this had become “normal life” for them, I was very impressed by the extraordinary care and commitment carers were giving within their family (often 24/7) and the contribution this also makes to our health care system and society generally. Thank you all again for sharing your time, experiences and wisdom with me.

This summary has 3 parts: (i) some general information about the people who took part in the study; (ii) a description of the process of learning to manage technical health procedures at home; (iii) the process of ‘embracing care.’

1. The participants

26 family carers

- 21 females, 5 males
- 11 aged under 40; 13 aged 40-65; 2 aged over 65
- Most identified as New Zealand European (18); 2 as New Zealander; 2 Samoan; 1 Māori; 4 of other ethnicities (1 person belonged to 2 ethnic groups)
- Most (20) were caring for their child; 3 for their spouse; 2 for a parent and 1 for a grandparent
- They managed a wide range of procedures:
  - Gastrostomy and/or jejunostomy feeding (e.g. PEG, MicKey button, PEJ) 12 carers
  - Nasogastric or orogastric feeding 9 carers
  - Type 1 or 2 diabetes management 7 carers
  - Enemas or bowel washouts 5 carers
  - Urinary catheter management 5 carers
  - Portacath or central venous line 3 carers
  - Suctioning 3 carers
  - Injections other than for diabetes 3 carers
  - Tracheostomy care 1 carer
  - Peritoneal dialysis 1 carer
  - Stoma management 1 carer
  - Continuous positive airway pressure (CPAP) 1 carer
- 12 carers managed 1 procedure; the remainder managed 2-4 procedures (either at the same time or at different times)
15 health professionals

- 14 females, 1 male
- 4 aged 20-39; 10 aged 40-59; 1 aged 60 or over
- Most identified as New Zealand European (13); 1 as Māori; 2 as other ethnicities (1 person identified with 2 ethnic groups)
- Professional roles: nurse (12); dietitian (2); occupational therapist (1)
- Between them, could teach all the above procedures

2. The process of learning to manage technical health procedures at home

A. An initial period of intensive training

- This took place in hospital, outpatient and/or home settings.
- There might be one teacher or several, depending on the procedure and location/s of teaching.
- The most common method of teaching was for a health professional to show and explain a procedure then supervise the carer practising it. Carers mostly practised directly on their family member, but sometimes started on a mannequin or something else.
- Many (but not all) procedures also had some written instructions or pictures to follow, and occasionally, DVDs. Carers appreciated having information to refer back to.
- Health professionals tried to individualise their teaching to meet the needs of learners.
- Sometimes more than one family member received teaching; sometimes the ‘main carer’ learnt, then taught others.
- How much teaching time there was depended on how complex the procedure was and how long it took for the carer to be able to manage it safely.
- As well as the practical management of a procedure, teaching could also include broader information about a health condition; problem-solving and making decisions about treatment; and how to get and dispose of equipment supplies.
- For family carers, learning to manage a procedure was not just about knowing what to do; it was also an emotional experience.

B. ‘Novice’ carers

- Novice carers have taken responsibility for managing a procedure at home, but were still developing their skills, particularly with managing new situations or problems.
- They generally ‘stuck closely to the rules’ but might also be beginning to individualise procedures for their particular situation.
- There might be some ongoing teaching from health professionals (either regularly or just when the carer requested it). Carers also made use of additional information sources like the internet and other carers.
- Some carers had to learn to repeatedly do procedures that were unpleasant or painful for their family member. They coped with this in various ways, including ‘switching off’ their emotions while performing the procedure, focusing on the benefits of the procedure, humour, and seeking alternatives.
- Managing a technical health procedure was only part of a wider context of adjusting to and caring for health or disability needs in the family.

C. Becoming an ‘expert’ carer

- With sufficient time and experience, carers could become expert in managing a procedure for their family member. This was demonstrated by their clinical skills (which may become “automatic”), monitoring and recognition of changes and problems, and decision-making.
They had a detailed knowledge of how the person they cared for responds and how to tailor the procedure for their needs.

- At the same time, they were still learning, perhaps with some health professional teaching, but often from their own experience, using the internet and sharing with other carers.
- Families adapted to the ‘new normal’ of managing a procedure by developing routines and being organised, as well as finding ways to be flexible.
- Expert carers might develop advocacy skills.
- They might also teach others how to manage the procedure, including other family members, relief carers, school staff and even health professionals.
- Caring could come with costs (financial, physical, emotional, family and social) as well as positive experiences.

D. Carer – professional relationships

- Through the process of learning to manage a technical health procedure, relationships between carers and health professionals changed and developed.
- Initially, carers needed and valued the knowledge and expertise of health professionals to teach them how to manage a new procedure.
- Once carers were sufficiently competent to manage day-to-day, regular professional input generally began to reduce. Sometimes this happened immediately following initial training; other times there was ongoing support with a gradual reduction over time. However, carers could continue to contact professionals on an ‘as required’ basis for further advice and support and to obtain equipment supplies (although after-hours access was limited for some and could mean dealing with unfamiliar personnel).
- For health professionals, decreasing their regular support for carers and moving to reactive rather than proactive contact was a practical necessity of their workloads and having to prioritise needs, but they also stressed their continuing availability for back-up support.
- When carers have become experts and their expertise is appropriately recognised by health professionals and vice versa, the two parties can act in partnership. Each has different but complementary expertise: carers know their family member well and how to manage a technical health procedure specifically for this person; health professionals have the ability to draw on a broader knowledge and skill base. For an effective partnership, each must be aware of their own skills and limitations, and trust and be willing to learn from the other.
- Carers gave examples of having their expertise recognised by health professionals and others, but some also spoke of having it devalued at times. Although carers’ expertise should be rightly recognised, they must also be able to get professional support when required and should not be expected to know or manage things beyond their skill level or their overall caring capacity.

3. ‘Embracing care’

Alongside and overlapping the learning process, another process was going on which I’ve called ‘embracing care.’ This is a way of describing how family carers experienced and responded to taking on the role of managing technical health procedures. They did this in 5 ways, set out below. These were not fixed positions – carers could change and move between them.

- **Accepting embrace** was about carers’ willingness to take on managing a technical health procedure. They were primarily motivated by the expected benefits for their family
member. There were 4 aspects of a procedure that could be embraced in whole or in part: understanding its purpose and benefits; accepting a ‘technical’ solution; learning to manage the procedure; and an emotional response to it. As well as embracing a new procedure, carers might also be letting go and grieving for other things (such as seeing their family member lose the ability to feed orally).

- **Carers who were resisting embracing** procedures weren’t convinced about their clinical benefit, didn’t believe it should be their role or that they could cope with managing them, and/or were still coping with their emotional reaction to the situation. Resistance might also be expressed as neglect. Being able to resist implies there’s an acceptable alternative (if not, carers may reluctantly embrace the procedure, or their family member might go into alternative care). Carers were most likely to resist managing aspects of a procedure which were distressing for their family member (like replacing a nasogastric tube, even if they were happy to give feeds through it).

- **Reluctant embrace** occurred when carers felt they had no choice, or the alternatives were even less acceptable.

- Some carers had **relinquished embrace** for a variety of reasons: the procedure was no longer needed or people chose to stop treatment; the family member learnt to self-manage, or they might go into alternative care, or die; the carer reached a point where they could no longer manage (and alternative care arrangements had to be made); and temporary relinquishment during respite care or when children were at school. However, while carers might relinquish hands-on care, they continued their emotional concern and oversight of the quality of any alternative care and often remained ‘on call’ if needed.

- Finally, carers could be **overwhelmed by caring**, including at times of crisis or when care was intensive and there is little support or respite.

- As noted above, carers could change positions at different times. Common movements were from resistance or reluctance to accepting embrace (especially if they experienced benefits afterwards) and from accepting to being overwhelmed, reluctant to continue or relinquishing care. Shifting positions may be related to changes in the intensity of caring and the availability or absence of professional support or respite. It shouldn’t be assumed that having accepted a caring role, people will necessarily want or be able to continue this forever, or that having embraced one procedure, they will want to manage others.

- “Choosing” to care is often constrained by limited alternatives. Family care is also occurring in the context of relationships and the assumptions and expectations families, health professionals and society hold about how family members should care for one another.

**And finally: Where to next?**

I am currently working on writing up these findings in more detail and hope to complete my PhD thesis by the end of 2014. I am also looking for ways to begin sharing the findings from this study, starting with a presentation at a Health Services and Policy Research Conference here in Wellington in December. I also plan to publish some journal articles so that the information is more widely available. I hope this will raise awareness about the importance and complexity of the role of family carers who manage technical health procedures at home and what they may need from the health system to support them.

Thank you again for contributing to this study.

If you would like to give any feedback or discuss these findings further, please get in touch with me (contact details in the attached letter).