

Advance Directives and Perspectives of Older People among Dunedin's Faith Communities

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Abstract

Advance directives (ADs) are written or oral instructions concerning future health care interventions such as life sustaining treatments. The aim of the research was to explore perspectives of older people from faith communities regarding ADs. The research questions included: 1) how older people described their experience with the end of life care of their loved ones, and how their faith tradition affected their views on end of life care; 2) what they considered to be benefits and disadvantages to advance care planning; and 3) their reasons for completing or not completing advance directives.

This project used a qualitative approach with a combination of focus groups and interviews. Twenty four older adults were recruited from diverse faith communities in Dunedin. Data analysis techniques included thematic, content and narrative analysis. Several strategies were used to enhance methodological rigour, such as, prolonged engagement, member checks, triangulation, peer feedback, audit trail, thick description, and reflexivity. Question One generated spontaneous findings namely, respondents experienced discomfort in talking about death and dying, and stories about rest homes were a gateway to such conversations. The two top fears were dying in pain, and dying in an undignified manner through permanent loss of cognitive abilities. The respondents' viewed God as the giver of life, they believed in an afterlife and emphasized the importance of religious rituals. On Question Two, the perceived benefits of ADs were improving communication, not being a burden to others, planning ahead, and ascertaining treatment options. Among the disadvantages were the AD limitations, communication difficulties, and problems with storage. On Question Three, the reasons for AD completion were death of a spouse, concern for family/survivors, autonomy - sense of control and empowerment, and having an independent personality. They also cited some reasons for not completing an AD such as fear of the unknown, avoidance, family expectations, faith in providers, and lack of information.

Practice implications for this study highlighted the need to improve communication about end of life care through storytelling, training of workers, and community outreach.

Keywords: advance directives, death and dying, end of life care, advance care planning, enduring power of attorney, older people

Preface

In May of 2009, my father died after a long bout with chronic illnesses including stroke, diabetes, glaucoma and prostate cancer. He was strong-willed, had a positive work ethic and was a veteran of World War II. When his illness progressed, my mother took care of him around the clock at my sister's home. My brother, who is a licensed vocational nurse, lived with them. After several conversations with family, dad completed an advance directive (AD) before he became mentally incompetent. He was enrolled in hospice, had palliative care, listened to his favourite compact disks (CDs) and except for some agitation, his pain was managed quite adequately. He had the best care California could offer. So upon receiving my brother's phone call one early morning, my strongest feeling was that of relief. My dad had experienced what I would consider a *good* death.

Oftentimes, people say that when it comes to the "personal," the "professional" goes out the window. In dad's case, my personal and professional backgrounds actually worked in tandem with one another. I had been involved in end of life care and bereavement since the 1990's as a hospital chaplain in U.S. hospitals. My wife and I completed our own individual ADs in 1995 and I had been talking to church members, co-workers and family about the value of advance care planning. Being new to New Zealand, I was curious about how older people in Dunedin viewed future health care planning. I was surprised to find out that few of the people I knew were familiar with the term "advance directives" (ADs) although they knew more about "enduring power of attorney" (EPA). Nevertheless, in a retrospective study of patients who died at Dunedin Hospital in 2003, Glasgow, McLennan, High, and Celi (2007) ascertained that end of life discussions were documented in 82% of the cases, 74% had a do-not-resuscitate (DNR) order and 67% were pain free. The authors suggested that communication, socialised health care system, societal expectations and lack of a litigious culture promote better care at the end of life. Moreover, the Quality of Death Index measuring end of life services across forty countries (thirty from OECD nations) ranked New Zealand third in the overall quality of death, just behind the UK and Australia (Economist Intelligence Unit, 2010).

So based on personal experience and professional interest, I was keen on exploring and understanding older people's perspectives on end of life care.

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TABLE OF CONTENTS

Abstract	ii
Preface	iii
Acknowledgements	iv
Table of Contents	v
List of Tables	viii
List of Figures	ix
Chapter 1 Introduction	1
Chapter 2 Literature Review	3
Philosophical Underpinnings	3
Benefits of ADs	4
Limitations of ADs	5
Advance Directives in New Zealand and Australia	6
Factors influencing AD completion	8
Religious factors	9
Cultural factors	10
Research plan	11
Postmodernist framework	11
Aim of Research	13
Conclusion	13
Chapter 3 Methods	15
Design	15
Recruitment	15
Data collection	17
Data analysis	17
Prolonged engagement	18
Member checking	18
Peer review	19
Triangulation	19
Audit	19
Thick Description	19
Reflexivity	20

	Content analysis	20
	Narrative analysis	21
	Conclusion	22
Chapter 4	Findings	23
	Respondent Profile	23
	Question One	24
	Spontaneous findings	25
	Death and dying	27
	Faith traditions	28
	Question Two	30
	Benefits of advance directives	30
	Disadvantages of advance directives	32
	Question Three	33
	Reasons for AD completion	33
	Reasons for not completing an AD	34
	Talking about death and dying: content analysis	36
	Narrative analysis	38
	Case 1 Planning ahead	39
	Case 2 Independence	44
	Case 3 Family conversations	48
	Case 4 Preferences in end of life care	51
	Conclusion	55
Chapter 5	Discussion	57
	Reflections on methods	57
	Limitations of the study	58
	Key findings	59
	Communication issues	59
	Discomfort	59
	Rest homes	59
	Other communication difficulties	60
	ADs as a communication tool	61
	Strong local family support	61
	Family obligations	62
	Family conflicts	62

	Family conversations	63
	Faith and faith community	63
	Faith and action	63
	Church as extended family	63
	Death as transition	64
	Autonomy	64
	Sense of independence	64
	Planning ahead	65
	Treatment preferences at the end of life	65
	Peer feedback	69
	Conclusion	70
Chapter 6	Conclusion	71
	Summary	71
	Practice Implications	72
	Storytelling	72
	Training of workers	73
	Community outreach	73
	References	76
	Appendices	
	Appendix A Research Approval	
	University of Otago Ethics Committee Approval	86
	Ngāi Tahu Research Consultant Committee Approval	87
	Appendix B Documents for Participants	
	Information Sheet for Focus Group participants	89
	Consent forms	92
	Appendix C Focus Group Protocols	
	Focus Group Guide Questions	94
	Revised Focus Group Guide Questions	95
	Appendix D Participant Information Sheet	96
	Appendix E Chi square Analysis between Genders	98
	Appendix F Published Article	100

List of Tables

Table 1 Respondent Characteristics	23
Table 2 List of Respondents	24
Table 3 Experience of loved ones in rest homes	26
Table 4 Talking about death and dying	36
Table 5 Functionality of Clauses	38
Table 6 Lyn's Function of Clauses	43
Table 7 Betty's Function of Clauses	47
Table 8 Summary of Lisa and Craig's Discourse	51
Table 9 Greg and Barbara's Function of Clauses	54

List of Figures

Chart 1 AD: A process in decision making	68
Chart 2 Community Outreach	75

CHAPTER 1

Introduction

An advance directive as defined in the New Zealand Code of Health and Disability Services Consumers' Rights (the Code) is "a written or oral directive --- (a) by which a consumer makes a choice about a possible future health care procedure; and (b) that is intended to be effective only when he or she is not competent" (HDC, 2009a). Moreover, in accordance with section 11 of the New Zealand Bill of Rights Act of 1990, every consumer may exercise Right 7(7) of the Code "to refuse services and to withdraw consent to services" (HDC, 2009a). ADs may include the withholding or withdrawing of life sustaining treatment as stipulated in an Advance Directive for Health Care document, and/or declining cardio-pulmonary resuscitation (CPR). The latter is referred to as a patient initiated do-not-resuscitate order (DNR) (HDC, 2009b). These procedures only take effect when patients lose their mental capacity due to trauma, illness or critical event (HDC, 2009a). The validity of the directives depend on four requirements: patients must have mental competence when the decision was made; there must be no undue external influence; sufficient information should be provided; and lastly, patients must have intended to have the directives applied to the current circumstances (HDC, 2009a, HDC, 1997).

Consumers can authorise attorneys to act on their behalf when they become mentally incompetent through the Enduring Power of Attorney (EPA) in relation to the Protection of Personal and Property Rights Act 1988 Welfare (PPPR Act) (Coates, 2002). This route however, necessitates high legal fees which are cost-prohibitive for many consumers. Moreover, the designated attorney may not refuse standard medical treatment or life saving interventions (Thomas, 2001; Coates, 2002; HDC, 1997).

The enforcement of patient directives is limited in some circumstances. For instance, the New Zealand Medical Association (NZMA) explains that patients cannot refuse in advance, a compulsory treatment under the Mental Health Act; nor can they demand euthanasia or assisted dying. Also, advance requests for specific treatments lack legal weight if clinicians assess that the treatment is inappropriate (NZMA, n.d.). Still, an AD can be valuable in ascertaining patient values, treatment preferences, palliative care and the like. Other countries use terms such as "Living Wills" or "Declaration to

Providers,” and “Durable Powers of Attorney for Health Care” to designate a surrogate decision maker.

Many from the legal community have therefore, recommended the completion of both AD and EPA to expand protection of consumers’ health care choices when facing life-limiting conditions (Thomas, 2001; Coates, 2002). Upon determination of mental incapacity, the EPA and AD would set into motion a decision making process involving attorneys to act on behalf of the patient with regard to property and personal care, as well as instructions with regard to refusal of certain life-sustaining treatments.

The use of advance directives in New Zealand is slowly improving. The Health and Disability Commissioner produced the “Health Passport” workbook for consumers to help them gather vital information about their health needs as well as ADs. Advance directives need to be situated in the greater framework of advance care planning which the Ministry of Health describes as a “process of discussion and shared planning for future health care that assists the individual to identify their personal beliefs and values and incorporate them into plans for their future health care” (Ministry of Health, 2011). In addition, advance care planning suggests that the conversations are not limited to the acceptance or rejection of certain treatments but to what patients deem acceptable in terms of quality of life (Meier and Morrison, 2002). In June 2010, the National Advance Care Planning Cooperative (Manson, 2011) was formed by health care professionals to “develop a common understanding, framework and direction for Advance Care Planning in all areas of health, for our communities” (CMDHB, 2012). Lastly, the website, www.advancereplanning.org.nz contains practical materials, planning guide, instructions that describe the kind of care they would want (or not want) if they are unable to speak for themselves (Advance Care Planning Cooperative, 2011). Among clinicians, Dr. Barry Snow, head of adult medicine at Auckland Hospital and his colleagues hope to see advance care planning promoted in GP clinics and hospitals across the country (Johns, 2011). So during this formative stage, it is timely to explore the different perspectives of older adults regarding advance directives and advance care planning.

CHAPTER 2

Literature Review

The literature review discusses the philosophical underpinnings of advance directives, the New Zealand and Australia context, and factors that influence AD completion particularly, religious and cultural factors.

Philosophical underpinnings

Advance directives in western countries are based on the principle of liberal autonomy (HDC, 2009a; Ikonomidis and Singer, 1999; Singer et al., 1998) and the patient's capacity to decide whether to accept or refuse future medical treatment, such as life sustaining interventions without external coercion (Tiano, 2012; Jonsen, Siegler and Winslade, 2006; Cohen, 2005; Tiano and Beyer, 2005; Wareham, McCallin, Diesfeld, 2005; Werth, 2005; Fisher, Tulsky and Arnold, 1995). Based on the notion that individuals have moral personhood, autonomy refers to the respect for persons and assumes that the individual has competency to make health care decisions (Miller, 2004) which is a logical extension of the doctrine of informed consent (Fisher, Tulsky, and Arnold, 1995). The capacity for self-determination allows people to "take control over and have responsibility for their lives and the kind of persons they become" (Brock, 1995). In New Zealand, the courts have upheld the right of a competent adult individual to refuse medical treatment not only for rational reasons but also including the irrational, unknown or even non-existent (Thomas, 2001). Hence, in contrast to paternalism where decisions are made by health care providers, ADs and informed consent imply that the procedure's risks, benefits and alternatives have been discussed with the patient and that he or she consents to the said procedure. Ethical dilemmas often arise when patients are mentally incapacitated and they have no ADs. In such cases it is best to consider some ethical guidelines for clinicians and consumers (Gillett, 2009). Health care decisions are usually made through the following standards for surrogate decision making: substituted judgement or patient's best interest (Jonsen, Siegler and Winslade, 2006). In substituted judgement, surrogates such as the next of kin or family present need to consider the patient's values and preferences based on their knowledge of her or him. If the patient's wishes are unknown, the best interest standard may be applied which includes consideration of the individual's welfare, pain and suffering, and quality of life to the

extent that a reasonable person in a similar situation would likely prefer (Jonsen, Siegler and Winslade, 2006). Still, both standards are beset with difficulties including family disagreements over the patient's preferences, community and societal expectations, and stereotyping and discrimination.

Benefits of ADs. Thus, as mentioned above, ADs empower consumers to exercise their autonomy and be aware of their health care choices. Teno, Lindenmann, and Lynn (1994) proposed that the overall goal of advance care planning is “to ensure that clinical care is shaped by the patient's preferences when the patient is unable to participate in decision making” (p. S33). Rather than being reduced to a medico-legal form to fill out, ADs should be framed as a conversation between consumers and their families/whānau, health care providers, and friends. Advance care planning underscores the patient's personal values, beliefs, treatment preferences and goals of care (Cooke, 2012). These conversations may include clarification of documents, implications of palliative care, organ donation, hospice care and others.

There is evidence that family members also benefit from the advance directive process. One study conducted in north western U.S.A. shows that stress was highest among bereaved family members when the decedents did not complete their ADs and conversely, the completion of ADs reduced family stress during their time of grief (Tilden, Tolle, Nelson, Fields, 2001). Family members were invited to participate in individual interviews shortly after their loved ones died and then in follow up interviews six months later. The study sample included fifty one decedents, primarily white non-Hispanic, married, middle-class with the gender nearly equally represented. Seventy four family members participated in the first interview and sixty five completed the follow up interview. Family stress was measured using the Horowitz Impact of Events Scale. The results revealed that 35% of the decedents did not express end of life care preferences, 37% verbally communicated their wishes to family members and 28% wrote their ADs. The authors highlighted the significance of the influence of ADs as follows: “Family stress was highest in the absence of advance directives, was lower when verbal advance directives guided the family, and was lowest when written advance directives guided the family” (Tilden et al., 2001, pp. 105-115).

In another study by Abbott, Sago, Breen, Abernethy, and Tulsky (2001) involving a cohort of 102 critically ill patients whose life support were removed, family members were interviewed about their experience a year after the event. The setting was in six

intensive care units (ICUs) of a large tertiary academic medical center at Duke University. From a cohort of 102 patients, forty eight family members agreed to participate and their interviews were taped and coded. Sixty three percent of respondents had previously spoken with patients regarding their end of life care treatment which helped lessen the burden of decision-making. Families felt relieved that the patients had earlier made the decisions on withholding or withdrawing life sustaining interventions. One even commented: "...I did not... sign a single paper from the time he started, he did it all" (Abbott et al., 2001, p. 198).

Lastly, the last year of life has been associated with high costs in health care and service utilisation in many nations including New Zealand (Chan, Jackson, Doone, and Anderson, 2011). By minimising unwanted treatments, ADs may reduce overall health care costs.

Limitations of ADs. Nevertheless, Dr. P. Malpas of the University of Auckland's Medical and Health Sciences, quickly points out some of the limitations of ADs. While she favours promotion of advance directives, she advises caution, especially when dealing with older people (Malpas, 2011). They may be confronted with ethical challenges which include: ageist attitudes (rationing of health care resources), general practice setting and time constraints, and concerns regarding oral directives and mental capacity at the time of AD completion (Malpas, 2011). Over twenty years ago, researchers of the major study conducted from 1989 to 1991 among five U.S. hospitals called SUPPORT: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments found "no significant association between the existence of advance directives and decisions about resuscitation" (Teno, Lindenmann, and Lynn, 1994, p. 5). Others warn that the concept of advance directives may be "fundamentally flawed" (Perkins, 2007) because prior instructions may become irrelevant due to the unpredictability of medical care. Furthermore, though well-intentioned, advance directives and living wills may fail to consider the many contingencies in a health care crisis which cannot be captured in a directive such as withholding or withdrawing treatment (O'Reilly, 2009). There are also those who perceive that ADs are a convenient way to limit care due to cost containment.

Practical problems may also arise, such as patients not fully understanding the document, ADs not readily available or misplaced when needed, physicians not wanting to introduce the topic, and family disagreements (Fisher et al., 1995). Teno, Lindenmann, and Lynn (1994) ask: should autonomy always take precedence over other ethical

principles such as beneficence and justice? What about collective societies that place more value on tribal rather than individual decisions? Nevertheless, critics and proponents agree that despite these shortcomings, conversations between consumers and providers that recognize emotions, and build consensus on end of life decisions are valuable and necessary (O'Reilly, 2009).

Advance Directives in New Zealand and Australia

This section discusses the legal background and research surrounding ADs in New Zealand and Australia. Cartwright (2007, p. 114) observed that a systematic literature review of the term, “advance directives” found that most of the studies in this area were conducted in the US, followed by Australia, UK, Canada, and a very small number from New Zealand. Indeed, an internet search of the term “advance directives” and “New Zealand” of peer-reviewed articles from 1999 to 2012 using the article databases at the University of Otago Library yielded only a handful of results. The “Academic OneFile” had two articles: one was used in this Literature Review and the other was not included because it focused more on informed consent in the U.S.A. The “Academic Search Complete” had four articles: three of which were used in the Literature Review and the other was excluded because it was about psychiatric advance directives. “Google Scholar” yielded fifteen articles but only four were relevant and included in this study.

As regards legal background, ADs in New Zealand are based on the NZ Bill of Rights 1990 and common law (HDC, 2009). On one hand, the absence of AD legislation allows flexibility in presenting individual preferences without being weighed down with restrictive and rigid standardised forms. However, the lack of legislation and lack of accompanying sanctions may make it more difficult to require doctors to follow patients’ ADs (Thomas, 2001). Some of the ethical challenges of the New Zealand ADs (Malpas, 2011) and new initiatives on advance care planning (CMDHB, 2012) have been described above.

A unique feature of ADs in New Zealand is the nation’s bicultural society, with key groups being Māori and European. Māori perspectives on health models and collective decision making, which at times mitigate against completion of ADs (Wareham, McCallin and Diesfeld, 2005). Recent efforts by Midland Cancer Network (2011) and Te Korowai Hauora o Hauraki (Johns, 2011) to explore providing palliative care among Māori in their homes seem to be making inroads. This issue will be highlighted under “Cultural perspectives” below and in the Discussion Chapter.

In contrast to New Zealand, advance directive legislations in Australia differ in various states. In 1983 South Australia repealed the Natural Death Act in 1983 and replaced it with the Consent to Medical Treatment and Palliative Care Act in 1995 (Thomas, 2001). The Northern Territory and Victoria enacted the Medical Treatment Act in 1988 and subsequently amended it over the years. The Australian Capital Territory's Medical Treatment Act was enacted in 1994 and specifically deals with ADs. The documents were non-uniform and non-legally binding in many Australian states (Middlewood, E. Gardner, and A. Gardner, 2001). For example, New South Wales, Tasmania and Western Australia do not have advance directive legislations (Biegler, Stewart, Savulescu, and Skene, 2000; Cartwright, 2007). Even so, common law provisions for informed consents, and substitute decision-making such as power of attorney for financial and personal/health care exists in all Australian states (Setterlund, Tilse, & Wilson, 2002). Cartwright further emphasizes that despite the strong support for advance care planning, it is still not well understood and in fact, is underutilised. She calls for uniform national legislation, and mutual recognition of instruments, guidelines for preparation, storage and implementation of advance directives (Cartwright 2007, pp. 113-116).

Generally, research on advance directives in Australia during the early 2000s had been described as "scant" (Middlewood et al., 2001). Researchers at the oncology unit at Canberra Hospital recommended the urgent provision of information to patients and families regarding participation in decision-making to promote a "public debate in Australia to drive legislation for advance directives throughout the Australian states and territories" (Middlewood et al., 2001). In discussing the status of advance care planning, Taylor and Cameron point out the inappropriate use of treatment for terminally ill patients, such as cardio-pulmonary resuscitation (CPR) and other life-sustaining interventions including artificial nutrition and hydration (Taylor and Cameron, 2002).

Setterlund, Tilse and Wilson from the School of Social Work and Social Policy at the University of Queensland explored older people's knowledge of substitute decision making legislation (Middlewood et al., 2001). They collected data from forty eight focus groups and twenty nine individual interviews of older adults between the ages of sixty six to eighty five years old. The majority of their subjects particularly among the lower income and those with a major disability lacked access to information and knowledge of the enduring powers of attorney. Some preferred to cede control to families or health care

professionals, thereby, limiting their ability to participate in the health care decision-making process (Middlewood, et al., 2001).

In South Australia, public health professionals surveyed 90 randomly selected aged care facilities regarding their advance directive and palliative care policies (Brown, Grbich, Maddocks, Parker, Roe, and Willis, 2005). They also interviewed sixty nine residents from seventeen facilities which revealed that 87% had completed a legal document such as an enduring power of attorney. Others had a medical power of attorney (7%), a palliative care order (16%), and living will (3%). Researchers noted, however, that there was little consistency in the documentation of the residents' end of life wishes; some did not have palliative care policies and only a few facilities required a formal advance directive.

Factors influencing AD completion

Numerous studies across the U.S. cite age as the most influential factor in AD completion (Straw and Cummins, 2003; Dinger, 2005; AARP, 2008). For instance, Teno, Grunier, Schwartz, Nanda, and Wetle (2007) conducted a national study among those who died in a nursing home, hospice, or home and found that out of 1,587 patients with a mean age of 79 years, 70.8% had an advance directive. Yang, Hardwick, Tiano, and Pettis (2008) assessed the completion rates of advance directives in Nevada in 2008 through the Nevada Behavior Risk Factor Surveillance System (BRFSS). This state wide cross-sectional telephone survey of 4,461 respondents revealed age as the strongest predictor of advance directive completion. Using weighted multiple logistic regressions, researchers noted that those who were fifty five years and above, thirty five to fifty four years, and eighteen to thirty four years had completion AD rates of 55.88%, 25.80%, and 11.74% respectively.

Other contributing factors include: conversations between the providers and patients with regard to their preferences; and presence of a serious medical condition. In an earlier study by Gordon and Shade (1999), sixty five years and older members of a health maintenance organisation (HMO) were posted a mailed questionnaire to determine their end of life care preferences and advance directive completion. Using multiple logistic regressions, out of 5,117 seniors who were surveyed (80% response rate), one third reported having filed an AD with the HMO. However, only 15% indicated that they had talked with a provider about their end of life care preferences. Their data demonstrated a significant association between the latter and increased AD completion. Educational

interventions to older adults have also increased their AD completion rate (Gina, Dubois and Wagneur, 2008).

Finally, the importance of personal belief (Barusch, 2010) and training of professional caregivers cannot be overemphasized. For example, death anxiety among oncology social workers was shown to inhibit communication of ADs to patients. As their death anxiety increased, the ability to disclose information about ADs decreased (Marlys, 2009). Nevertheless, training of social workers improved patients' understanding of AD forms (Luptak and Boulton, 1994) and resulted in a significantly higher association between patients' wishes and treatments they received (Morrison, Chichin, Carter, Burack, Lantz, and Meier, 2005). Interestingly, in a litigious society like the U.S.A. (Glasgow, McLennan, High, and Celi, 2007) it seems that renewed interest in ADs emerge during legal court battles regarding end of life care. For example, the Cruzan case paved the way for the Patient Self-Determination Act in 1991 which requires all hospitals receiving federal funding to ask new patients if they have completed an AD. Later on, in 2005, the Schiavo case sparked a nationwide debate on ADs and incited the involvement of the U.S. Congress. Both cases have religious and cultural dimensions (Colby, 2005) which the next section expounds.

Religious factors. This next section discusses how religious beliefs of various denominations influence AD completion. Some groups such as Jehovah's Witnesses refuse blood transfusion even to save a life, and Christian Scientists do not seek medical care (Tiano and Beyer, 2005). In writing about religious advance directives, Grodin (1993) described case studies involving religion and medicine as being on a continuum. On one end are faith communities that operate outside the secular health care system and on the other end are religious groups that tend to work within the system while protecting their practices. Also, within this continuum are the "right to die" as well as the "right to life" groups. Roman Catholics do stipulate that in some circumstances, patients may refuse heroic interventions:

a person may forego extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community (USCCB, 2001).

In contrast to euthanasia, which is an intentional action or omission that causes the death to eliminate suffering, the former allows natural death to occur (Seper, 1980). Hence,

foregoing extraordinary interventions is not killing but allowing to die (McCormick, 1997). However, a controversy arose in 2004, when Pope John Paul II stated that it is morally obligatory to provide food and water even by artificial means to patients in vegetative state (John Paul II, 2004). At issue is whether failure to do so is deemed “euthanasia by omission.” The Vatican weighed in and maintained this argument during the case of Terri Schiavo, a Roman Catholic who was determined to have been in a persistent vegetative state since 1990 (Vinci, 2005). Understandably, the Pope’s statement became controversial, especially amongst Catholic hospices which have been on the frontlines of providing end of life care. This remains a contentious issue in Roman Catholicism today.

Protestants generally oppose euthanasia but allow withholding or withdrawing of life sustaining treatment for those who are actively dying. Authorities among Jewish Orthodox agree that once a ventilator has been introduced, it should not be stopped or removed even in cases of brain death (Tiano and Beyer, 2005). Conservative and Reform Jews, however, may allow for the withdrawal of life support systems including medical treatments such as artificial nutrition and hydration if they are not beneficial (Dorff, 1998). They have their own versions of advance directives. Understandably, Grodin concludes that specific religious instructions are unnecessary and may even be a hindrance. Instead, he argues for the use of a patient proxy and proposes early discussions of health care decision making where law, medicine, ethics and theology be considered to ascertain the patient’s best interest (Grodin, 1993).

Lastly, it is essential to distinguish between religion and spirituality, where the latter is more personal and not dependent on church membership. In a recent representative population-based study of 1,011 New Zealanders about palliative and hospice care, Macleod, Thompson, Fisher, Mayo, Newman, and Wilson, (2012) noted that while only 20% considered religion to be high or very highly important, 34% or one third considered spirituality to be high or very highly important in their lives. An article in the *International Journal of Palliative Nursing* observed that spouses, family members and sense of spirituality were the most influential determinants of AD completion among hospitalized patients in East Texas (Duke, Thompson and Hastie, 2007).

Cultural factors. While advance directives may be relevant in western countries where autonomy is highly valued, those that are more community orientated, such as

Japan, China, Italy and Israel are more driven by beneficence (Tiano and Beyer, 2005). Additionally, the liberal autonomy principle has been criticised by some Asian writers (Chan, 2004) because it is highly individualistic and it does not adequately promote shared family decision-making. Chan proposes an ethic of care using a familial model based on the works of Confucius and Mencius which has some affinities with “relational autonomy” from feminist theory. He proposes the use of Familial Advance Directives where the AD can be signed by the individual together with the family members (Chan, 2004, p. 97). Nevertheless, as Chan mentioned, even this model has its challenges because of family conflicts and dysfunction.

But an ever bigger problem seems to be the fact that conversations about death and dying are often taboo in many cultures. Among Native Americans such as the Navajos, direct conversations regarding diagnosis, grim prognosis and ADs may be damaging because of their strong belief that negative information is harmful (Carrese and Rhodes, 1995). Hospice New Zealand has been working with Māori to develop the standards for palliative care (Hospice NZ, 2012). These included holding hui (meetings) with Māori elders in line with the principles of the Treaty of Waitangi. Greater emphasis was made on collaboration, partnership and a more holistic approach to health promotion as proposed in Durie’s “Te Whare Tapa Whā” (4 sides to a house) which include: taha wairua (spiritual well-being), taha hinengaro (mental and emotional well-being), taha tinana (physical well-being) and taha whānau (family/human relationships) (Durie, 2005). The Hospice New Zealand Standards for Palliative Care released on 13 April 2012 contain whakatoki (Māori sayings) which were gifted by Māori elders from across the country (Hospice NZ, 2012).

Research plan

Having considered the underpinnings of ADs, its advantages and limitations, legal and historical context, AD completion and the need for more studies in New Zealand, my research plan applied a postmodernist framework and outlined the research aims in the next section.

Postmodernist framework. Creswell (1998) considers postmodernism a family of theories which was a critique to 19th-century Enlightenment and early 20th-century reliance on positivist and scientific method. Postmodernist thought thrives within the social sciences and insists that there are “multiple perspectives of class, race, gender, and other group affiliations” (Creswell, 1998, p. 79). As well, in contrast to the notion of a

single “truth”, Guba and Lincoln argue that “we stand at the threshold of a history marked by multivocality, contested meanings, paradigmatic controversies, and new textual forms” (Lincoln and Guba, 2008, p. 281) which emancipates researchers from hearing and seeing the world in one colour.

As expected, qualitative research has been criticised by positivists as being soft, suspect, more journalistic rather than scientific, exploratory, subjective, or politically, as Marxism or secular humanism in disguise (Denzin and Lincoln, 2008). Nevertheless, the case for qualitative analysis has been vigorously argued for nearly four decades (Denzin and Lincoln, 2008; Lincoln, 2010). Barusch, Gringeri and George (2011) noted the dramatic increase with the use of qualitative methods in social work dissertations between 1982 to 1992. Proponents describe themselves as interpretivists, postmodernists, and poststructuralists. While qualitative researchers may not have their own distinct set of methods they use a variety of approaches including narrative, content, discourse, archival analysis as well as statistics, tables, graphs and numbers. Additionally, they draw upon the techniques of phenomenology, hermeneutics, feminism, ethnography, survey research, participant observation and others (Denzin and Lincoln, 2008). A qualitative study is interested in the detailed, complex and holistic picture of the inquiry in a natural setting (Creswell, 2009; Creswell, 1998) and understanding multiple realities (Lincoln and Guba, 1985). This approach uses distinct methodological traditions in data gathering and analysis, including both “visual and verbal (conceptual or thematic) rather than numerical data manipulation” (Long and Godfrey, 2004, p. 183). Additionally, the researcher is the primary instrument in data collection (Creswell, 2009) and the data are used to understand more in-depth meanings tied to events, social contexts, processes and outcomes. As Reissman (2008) put it, “through our presence, and by listening and questioning in particular ways, we critically shape the stories participants choose to tell” (p. 50).

In “Naturalistic Inquiry,” Lincoln and Guba (1985) notably proposed the following criteria for qualitative research, namely, credibility, dependability, confirmability and transferability. Ten years later, Lincoln (1995) revised these criteria and described them as “foundational” due to its basis on empiricist and postempiricist research. She uses the metaphor of a researcher as quilt maker or jazz improviser to describe the new emerging criteria which embrace three commitments:

...first, to new and emergent relations with respondents; second, to a set of stances - -- professional, personal, and political --- toward the uses of inquiry and toward its

ability to foster action; and finally, to a vision of research that enables and promotes social justice, community, diversity, civic discourse, and caring (Lincoln, 1995, pp. 277-278).

Riessman and Quinney (2005) in “Narrative in social work: A critical review” portray the “narrative turn” as cross-disciplinary and argue that the central theme is human interaction in relationship. They add that in spite of the absence of a clear-cut definition, narrative emphasizes the ‘how’ and ‘why’ as well as the sequence and consequence, not just the content or the fragmented thematic categories. The narrative analysis section in the Findings Chapter is informed by Riessman’s (2008) contributions to this field.

Aim of Research

A qualitative approach using a naturalistic inquiry (Lincoln and Guba, 1985) draws out essential viewpoints from older people based on the stories of their loved ones’ care at the end of their lives. Presumably, older adults show less fear and more acceptance of death than younger adults (Barusch, 2010). Hence, the aim of this research project is to explore perspectives of older people from faith communities regarding advance directives. This project addresses the following research questions:

1. How do older people describe their experience with the end of life care of their loved ones? How does having a faith tradition affect older peoples’ perspectives on end of life care?
2. What do they consider the benefits and disadvantages to advance care planning?
3. What were their reasons for completing or not completing advance directives?

The potential contribution of this project to social work practice is two-fold. First, it addresses a gap in the professional literature. As mentioned earlier, little research has been conducted on the topic of advance directives in New Zealand. Second, this project should help inform policy and practice related to end of life care for older adults by contributing to a better understanding of why some older people are reluctant to complete ADs, despite their advantages; and, on the other hand, to help identify factors that lead other older adults to complete ADs.

Conclusion

Among western countries, the value of autonomy underpins the necessity for advance care planning. Advance directives are embodied in the NZ Bill of Rights and they empower consumers to take active participation in their health care choices and decision

making. Undoubtedly, there are a host of complex issues associated with ADs including attitudes regarding death and dying, the development of medical technologies, religious and cultural factors, oral versus written forms, mental competency at the time of the directives were drawn, family conflicts and storage to name a few. Nevertheless, ADs can be valuable tools for enhancing communication between patients, families and medical providers. While New Zealand ranks third in the overall quality of death amongst Organisation for Economic Co-operation and Development (OECD) countries, the current research literature on use of ADs in this country has been minimal. Thus, it is difficult to gauge how older consumers appreciate the value of advance care planning. The aim of this research therefore, is to explore how older adults who are members of faith communities view ADs taking into account their current setting. The study will use a qualitative approach to seek to listen and understand their narratives and views on end of life care.

CHAPTER 3

Methods

This project was an exploratory study of older people from Dunedin churches, which sought to generate insights through careful consideration of people's lived experiences with regard to ADs. The details of the research methods used in the study are presented in this section.

Design

As stated earlier, the qualitative study did not intend to test a hypothesis or obtain generalisable data regarding older people's perception of ADs in New Zealand. The stories were both personal and familiar and included narratives regarding their experiences with rest homes, consents to treatment, deaths and funerals. The selection of the participants was based on the following inclusion criteria: males and females, sixty five years and above; members or attendees of Dunedin faith communities; they must have lived in the city for six months or more. Under the exclusion criteria were people who were sixty four years and below; those who were not Dunedin residents; those who did not communicate in English; those who lacked capacity to provide informed consent. Lastly, the issue of mental health advance directives was not addressed.

Prior to recruitment of participants, I submitted a "Research Consultation with Māori" on 22 April 2011 and obtained approval for my project from the University of Otago Ethics Committee in June 2011 with the reference number, 11/132 (see Appendix A "Ngai Tahu" and "Ethics Committee").

Recruitment

Twenty four participants were recruited from members or attendees of four Dunedin churches, namely, Presbyterian, Anglican, Roman Catholic, and Christian Churches. I met with the University of Otago Chaplain Coordinator who helped me identify local clergy from the denominations above whom he thought would express an interest in the study. I sent out emails to these clergy and made follow up phone calls to secure their permission to contact church members in that age category. I also sought

approval from my pastor to recruit participants in my church. Personal contacts, referrals and church announcements helped inform members about the project. They were then invited to volunteer to participate in group interviews.

No one I personally recruited declined to participate. Potential respondents were courteous and quite willing to help me with my study. In one congregation, another University of Otago chaplain gathered eight older people after their Friday morning mass. We went to their favourite coffee place and had the focus group there.

A member from another parish expressed interest in participating in a focus group, but since no one else signed up from their church, I regrettably informed her that we would not be able to pursue the study there. Another pastor contacted me towards the end of my data collection period but I had to decline since I already had reached a sufficient number of participants.

The sample was thus obtained through a process of self-selection. The data gathering was obtained during the months of June through October 2011. I conducted three focus groups, numbering between four to eight respondents per group. To protect their identity and encourage anonymity, pseudonyms were used. The first group was composed of Lyn, Amy, Peter and Paul. There were members of the same local church and the discussion was held after a Sunday morning service. The second group was composed of Betty, Lisa, Craig, Gina and Glenn who attended Catholic, Anglican and Presbyterian churches and regularly visited a community centre. The discussion was held at the centre on a weekday afternoon. I was introduced to the third group through a chaplain who belonged to the same church. Pene, Faith, Angela, Grace, Dan, Justin, Luke and I met at a cafe after a weekday morning mass.

I had four separate couple interviews, namely, Vince and Rosie; Earl and Cristina; Shona and Elizabeth; Barbara and Greg; and we met at their homes. I also made individual follow up interviews with Lyn and Betty in order to flesh out more in-depth descriptions of the reasons why they completed both ADs and EPAs.

The Information Sheet for the focus group participants were distributed (see Appendix B "Information Sheet") prior to the session. The sheet included a brief description and aim of the project; inclusion and exclusion criteria; professional responsibility of the researcher, confidentiality, expectations for participants as well as support and helpful resources; voluntary nature and freedom to withdraw from the study; as well as data collection and storage. As well, the signed consent forms (see Appendix B "Consent Forms") for focus group participants were collected before each session. These

reiterated respect for privacy and anonymity, and use of open-questioning technique by the researcher. Those who were interested to engage in individual follow up interviews provided their names and contact information on the consent forms.

The Information Sheet and signed consent forms for couple and individual interview participants had basically the same content with the focus group sheets.

Data Collection

For the focus groups, I used a semi-structured approach, and participants were encouraged to share stories about the end of life care for their loved ones. The discussions were held in a flexible and open-ended narrative format (see Appendix C “Focus Group Guide Questions”). The session began with an introduction to the purpose of the study and an invitation to share a story about a loved ones’ care the end of life. Respondents’ perspectives were explored, particularly how they viewed the benefits and disadvantages of advance care planning as well as whether their faith or beliefs influenced their views. I audio-taped each of the sessions and made notes to keep track of the process. At the end of each focus group a Participant Information Sheet was collected (see Appendix D). This had a section on demographics such as gender, ethnicity or racial group they most identified with, age, a question on whether they had completed an AD and/or EPA, and an optional question regarding their income range.

I used a similar approach and questions for the couple interviews. After the first focus group and three couple interviews, I realized a level of discomfort in starting a session on death and dying so I adjusted my first question to the topic of rest homes (see Appendix C “Revised Focus Group Guide Questions”). This less-direct approach proved to be more effective in generating discussions about end of life care.

After each focus group and interview, field notes were immediately written to capture the observations of the session such as setting, room setup, seating, lighting, noise level and other pertinent descriptions of the context. Emotional tone, silence, and general interaction were recorded.

Data Analysis

To add rigour and minimize bias in this research, several strategies identified in the literature were used (Barusch, Gringeri and George, 2011; Creswell and Plano, 2011; Creswell, 2009; Lincoln and Guba, 1985; Long and Godfrey, 2004; Robert Wood Johnson

Foundation, n.d.; Tiano, 2012). Evaluative tools such as the one developed by Long and Godfrey (2004) provided helpful guided questions pertaining to the contexts (theoretical, setting, sampling, and outcomes) as well as the data collection, analysis and potential research bias. The strategies I used in this study to help establish credibility included: prolonged engagement, member checking, peer review and triangulation. The use of an audit trail and thick description were used to help establish confirmability and external transferability, respectively. Creswell (1998) recommended at least two of these strategies for verifying qualitative research. In fact, Creswell and Plano (2011) assert that qualitative validity comes from the analysis of procedures conducted by the investigator and from external reviewers. Reflexivity was used throughout the research process to identify the researcher's beliefs, values and positions. Content and narrative analysis provided thematic categories, and different interpretations of participants' stories were explored.

Prolonged engagement. Prolonged engagement involves sufficient time, rapport, trust and confidence between the researcher and the participants (Creswell, 2009; Lincoln and Guba, 1985). Having been a member of one of the local churches for over a year, I knew or was acquainted with 16 of the 24 older adults and their families. I also have a wide understanding of church beliefs and feel comfortable talking with other clergy and their congregants about end of life care. My challenges therefore were to identify my preconceptions, co-construct meaning with participants and engage in respectful uncertainty rather than "cultural competency" (Dean, 2001). As an insider to the faith community I was mindful of Johnson's (2002) warning, that while members of a group may have a quicker learning curve, they (we) may also fall into the trap of assuming that their (our) previous knowledge is sufficient.

Member checking. Member checking refers to the process of testing the data, categories and interpretations with members of the groups (Creswell, 2009; Lincoln and Guba, 1985). Participants who were interested in reviewing the transcripts and categories were given the opportunity either through email or hard copy. Feedback was obtained through email correspondence, phone or personal contact. A limitation of this strategy is that members may later change their positions, deny some accounts, reframe or prefer that some stories be deleted. The six respondents who completed both ADs and EPAs had asked to see their transcripts and were provided with either electronic or hard copies. The

main feedback related to my spelling errors which included my attempts to use abbreviations for brevity. No one changed the substance of their accounts.

Peer review. Peer review provides an opportunity to test biases, categories and perspectives of the researcher with a peer group. I gave a presentation of my findings during the International Congress on Pastoral Care and Counselling in Rotorua, New Zealand on the 25th August 2011. The group's feedback will be examined in the Discussion section. Other researchers use "peer debriefing" which involves another person who provides a peer review to add validity to the investigation (Creswell, 2009). I preferred the term "peer feedback" for this study because of its specific usage during the said Congress.

Triangulation. Triangulation involves multiple data sources to obtain deeper understanding (Creswell, 2009; Patton, 1999). I used a 'methods triangulation' by comparing the similarities and differences between focus groups, couple interviews and individual interview.

Audit. Lincoln and Guba (1985) cite Halpern's dissertation on audit trails, which consist of all raw data (e.g. transcripts, field notes), data reduction and analysis products (e.g. summaries, condensed notes) data reconstruction and synthesis products (e.g. structure of categories), process notes (e.g. methodological notes), materials relating to intentions and dispositions (e.g. reflexive notes) and instrument development information (e.g. preliminary schedules). An external audit was done by an ecumenical chaplain at Capital and Coast District Health Board who works with gerontology/mental health and was not familiar with the project. She witnessed all the data transcripts, informed consents (focus group and interview respondents), field notes, process notes and reflections.

Thick description. Thick description was first used in ethnography and in this study pertains to the detailed accounts of the researcher's field experiences (Creswell, 2009; Creswell, 1998). The in-depth interviews described participants' stories with sufficient detail to evaluate transferability to other times and settings.

Reflexivity. I started this thesis with a short account of my dad's death and professional background to disclose that this study was not value-free, but part of an ongoing process of self reflection (Lincoln and Guba, 1985; Guba and Lincoln, 2008). Creswell (1998) explains that in a qualitative inquiry, "the writer brings himself or herself into the study, the personal pronoun 'I' is used" (p. 18). The use of reflexivity in data analysis and interpretation reveal the relationship between the interviewer and the interviewee, and the former's preconceptions, perspectives, beliefs and values. The 'reflexive turn' has shown the interconnectedness and interdependence of the data and the importance of not just *what* but *how* knowledge is learnt (Mauthner and Doucet, 2003, p. 416). Additionally, reflexivity is an ongoing process (Creswell, 2009; Riessman, 2008) where the researcher attends systematically "to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process" (Robert Wood Johnson Foundation, n.d., p. 12). Suffice it to say that the background and perspective of the researcher influence both qualitative and quantitative research and the investigation can be viewed as a kind of intervention in itself. Herein lies what sets apart qualitative from quantitative --- proponents of the former believe that research can never be separated from the "researcher's personal views and characterizations" (Creswell and Plano, 2011, p. 210).

An essential component of reflexivity was supervisory sessions, held mostly through Skype. These were held bi-weekly from the first semester 2011 when I began the MSCW programme until the end of the second semester. In 2012 we met around once a month and I kept my supervisor updated with my progress via email. The supervisory sessions were most helpful in providing direction, resources, focus, clarity as well as personal encouragement and motivation.

Content analysis. While there is no consensus in qualitative data analysis, Creswell (1998) highlights common features such as reviewing data, developing categories or coding, and using analytic frameworks. He notes diverse approaches to analysing data represented by five different traditions: biography, phenomenology, grounded theory study, ethnography and case study (Creswell, 1998; Creswell, 2009).

Hsieh and Shannon (2005) stress the content analysis of the text data through the "systematic classification process of coding and identifying themes or patterns" (p. 1278). The authors identify three distinct approaches which adhere to the naturalistic inquiry,

namely: conventional (coding categories derived directly from the text data), directed (initial codes guided by theory) and summative (keyword frequencies are noted).

The conventional and summative approaches were used in this project. The conventional approach drew from participants' actual responses with no preconceived categories. The method included a preliminary reading of the transcript followed by a more careful reading noting emotional reactions, key words/phrases and formulation of open coding. More new codes were added, combined or split into categories or subcategories. The codes were then organised into a more coherent structure if possible. This approach stops short of generating or discovering a theory which is the intent of a grounded theory study (Creswell, 1998; Hsieh and Shannon, 2005).

Summative content analysis was used to study frequencies of keywords or significant terms in the transcript. Of particular interest were the metaphors used for death and dying and the number of times they were used. The total number of those who have completed their advance directives and enduring powers of attorney were also tabulated.

Narrative Analysis. Fraser (2004) discusses the "narrative moment" in narrative research from critical social work to post-modernism where emphasis is given to plurality of truths, curiosity, and reflexivity among others. I sought to identify ambiguities, contradictions and contingencies which were vital in meaning-making as well as dominant stories and their influence on people (Milner and O'Byrne, 2009). Fraser (2004) proposes the use of different phases, namely, field notes, transcriptions, interpretations, and commonalities and differences among participants. Other written notes also paid attention to researcher's reflections, thoughts and feelings, curiosity and insight. Narrative analysis is basically case centred and interested in preserving the wealth of detail in the sequence of the narratives (Riessman, 2008, p. 74).

To ascertain the reasons why six of the participants completed both AD and EPA, I used a simplified version of structural analysis adapted by Riessman (2008) who cite the initial works of sociolinguists Labov and Waletzky's (1967) and James Gee's (1991). These approaches have been discussed at length by narrative researchers (Reissman, 2008; Wells, 2011; and Elliot, 2005). Over the years, Labov (n.d.) and Gee (2010) modified and further refined their methods, which were beyond the scope of this study. In any case, use of a structural analysis, albeit introductory, provided profound insights into the participants' values, circumstances and reasons which contributed to their advance care planning.

Conclusion

This project was exploratory in nature and utilised a combination of focus groups and interviews. Prior to the recruitment of participants, approval from the Ethics Committee of the University of Otago was obtained and the study was reviewed by the Ngāi Tahu Research Consultation Committee. Twenty four participants were recruited personally and through referral. The data were audio recorded, transcribed and analysed using diverse qualitative strategies. To help establish credibility, I used prolonged engagement, member checks, triangulation and peer feedback. Audit trail and thick description were used to help establish confirmability and external transferability. Reflexivity which included observations from process notes and reflections were used throughout the whole research process. Content analysis of the participants' vocabulary on death and dying classified common expressions and frequency of usage. Lastly, narrative analysis was used to ascertain relationships among words and phrases and to determine the context of participants' responses.

CHAPTER 4

Findings

This section reports on the findings that were in response to the three research questions. General themes and sub-themes were grouped under each question. Of particular interest were the spontaneous findings, vocabulary on death and dying and narrative analysis of the reasons why the six respondents completed both ADs and EPAs.

Respondent Profile

All the twenty four respondents were European-New Zealanders who lived in Dunedin. Their ages ranged from sixty five to eighty nine years old with a mean age of seventy five years. All were physically active, able to attend religious services and mentally competent. They received retirement and/or other income ranging from \$11,000 to \$51,000+ per year. Out of twenty four respondents, fourteen (58%) were females and ten (42%) were males. Four females (17%) including two widows, and two males (8%) completed ADs for a total of six (25%). These also completed their EPAs. Eight females (38%) including four widows, and three males (8%) completed the EPAs for a total of eleven (46%). The four oldest respondents who were in their eighties had EPAs. The respondents' profiles have been summarised in Table 1 (Respondent Characteristics) and Table 2 (List of Respondents) below.

Table 1 Respondent Characteristics

	Total	Male	Female
Respondents	24	42%	58%
Age (mean)	74.83 years	75.4 yrs	74.43 yrs
Age range	65 – 89 yrs	65 – 87 yrs	67 – 89 yrs
EPA Completed	45.8%	8.3%	37.5%
EPA not completed	54%	29%	25%
AD Completed	25%	8.3%	16.7%
AD not completed	75%	33.33%	41.67%

Table 2 List of Respondents

	Name (pseudonym)	Gender	Ethnicity	Age	EPA	AD	Income
1.	Greg	M	Euro/NZ	77	Yes	Yes	31k to 40k
2.	Barbara	F	Euro/NZ	73	Yes	Yes	Unk
3.	Betty	F	Euro/NZ	67	Yes	Yes	51k+
4.	Lisa	F	Euro/NZ	68	Yes	Yes	Blank
5.	Craig	M	Euro/NZ	74	Yes	Yes	Unk
6.	Lyn	F	Euro/NZ	75	Yes	Yes	11k to 20k
7.	Gina	F	Euro/NZ	67	Yes	No	21k to 30k
8.	Amy	F	Euro/NZ	85	Yes	No	Blank
9.	Peter	M	Euro/NZ	87	Yes	No	Blank
10.	Elizabeth	F	Euro/NZ	82	Yes	No	Unk
11.	Shona	F	Euro/NZ	89	Yes	No	Unk
12.	Pene	F	Euro/NZ	73	No	No	Unk
13.	Faith	F	Euro/NZ	75	No	No	51k +
14.	Angela	F	Euro/NZ	74	No	No	Unk
15.	Grace	F	Euro/NZ	73	No	No	11k +
16.	Dan	M	Euro/NZ	77	No	No	51k+
17.	Justin	M	Euro/NZ	76	No	No	51k+
18.	Luke	M	Euro/NZ	73	No	No	Unk
19.	Glenn	M	Euro/NZ	72	No	No	11k to 20k
20.	Paul	M	Euro/NZ	65	No	No	Blank
21.	Cristine	F	Euro/NZ	73	No	No	41k to 50k
22.	Earl	M	Euro/NZ	74	No	No	41k to 50
23.	Rosie	F	Euro/NZ	68	No	No	11k to 20k
24.	Vince	M	Euro/NZ	79	No	No	11k to 20k

With regard to gender differences and AD/EPA completion, a chi-square analysis showed no significance mainly due to a small sample size (see Appendix E). Over all, the respondents were a homogenous mix who represented a snapshot of European/New Zealanders. They have resided in Dunedin and have been active in their church and community for a number of years. Their responses covered broad perspectives of their previous generation and those of their own. As well, they disclosed intensely personal narratives of their losses which have helped shape their views on death and dying.

Question One: how do older people describe their experience with the end of life care of their loved ones? How does having a faith tradition affect older peoples' perspectives on end of life care?

The respondents' views were classified under spontaneous findings, death and dying and faith perspectives.

Spontaneous findings. The data that were not expected at the beginning of the study proved to be significant in understanding the respondents' viewpoints. These two spontaneous findings were: a sense of discomfort in talking about death and dying, and the issue of rest homes.

Discomfort. Generally, the first focus group (four respondents) and three couple interview respondents expressed discomfort in response to the question: *Would you share a story about a friend or a loved one's care at the end of life that has made an impression on you?* Their responses came in the form of: "Oh, I had not really thought about that" or "We don't talk about those things" or marked silence. One respondent said "he almost fell off his chair" when I introduced the topic. An 85-year old remarked that the subject matter was too personal and that it was none of her business. She then gave me a look which implied that it was none of my business either. I replied by sharing briefly about my father who passed on in 2009 under hospice care. He had earlier completed his advance directives and died a "good death" in his sleep at home in the company of his loved ones. This response seemed to give permission to other respondents to join in and talk about the loss of their parents. Others talked about what it was like for their relatives to be in rest homes.

Experience of loved ones in rest homes. I therefore, changed my opening question to "would you share a story of a loved one or a friend who had been in a rest home?" This query proved to be a better strategy for generating talk about end of life care.

Rest homes had both positive and negative connotations which were summarised on Table 3 as follows:

Table 3 Experience of loved ones in rest homes

Negative	Positive
Sense of isolation	Sense of community
Lack of space and privacy	Adequate space and privacy
Lack of cleanliness	Cleanliness
Institutionalisation	Autonomy and freedom
Rigid activities	Flexible activities
Lack of trained staff	Presence of trained and caring staff

There were negative stories about a sense of isolation particularly with those who had very few or no visitors. The lack of space and privacy were noted by an architect in the focus group who complained that many of the units were too small and lacked the use of creative spaces. Lyn, a 75 year-old widow who lived alone in her apartment protested: “they all seemed to be squashed into an arrangement in a skinny type of room... They’re all sort of on top of one another and there’s just a door that goes to the dining room... and it just looks so crammed”. The lack of cleanliness and bad smell added to the notion of being institutionalised. “Some of them are run like prisons” said Luke (73 years old) who was a co-owner of an 80-bed home and hospital. They decided to get out of the business because of the low funding from government contracts. Faith (75 years old) criticised some of the activities as too rigid saying that “there’s a lot of coercion for people to come together to play *housy* even if people don’t want to”. Several expressed concern for better trained and paid workers because of the long hours and work challenges. One was particularly distressed because her mother had special needs since she was deaf. Unfortunately none of the staff knew sign language. Finally, a woman in her late 60’s who was active in community work objected: “there are too many old people in the rest homes!”

On the other hand, there were positive views on rest homes as well. Craig (74 years old) described a group of homes that have changed their philosophy and approach to long term care to more of a community house model. He described as similar to living in a household.

Your meals are supplied for you but you live as an individual or as a husband and wife in a huge house. So the house might be divided into four levels with a lounge, living rooms and much like a youth hostel... and medical services are available as required.

Lisa (68 years old), his wife, added that residents have more autonomy and private space. She continued, “I think the difference is it’s a small number and people are in the

community and the library bus comes to you”. Gina (67 years old) likened it to some little apartments with communal facility “where people can have access to company and other things”.

The respondents who were Roman Catholics were very pleased with Catholic rest homes because of the nuns and religious services. Grace (73 years old) said that her mother “spent seven years in _____ (a Catholic facility) where she was beautifully cared for”. The familiar environment and proximity to the rest home made a huge difference. Similarly, the mother of Justin (75 years old) and Dan (77 years old) died in a Catholic rest home and they also described it as a beautiful experience.

Besides caring staff, small additions like having a resident cat also had a profound positive impact. Barbara (73 years old) recalled that her mother was much happier at the nursing home because the resident cat fell in love with her. Ironically, she was a person who disliked cats and in fact did not allow her family to raise cats.

While the place of death nowadays is often the rest home or hospital, quite a few participants expressed their preference for dying in their own homes. Three respondents in their 70’s echoed that this sentiment: “We’re trusting our Lord that we’ll just be able to die at home... and then down to the funeral parlour from there” (Luke, 73 years old). When asked why he wanted to die at home, one respondent exclaimed: “memories, memories, memories!” (Vince, 79 years old).

Death and dying. Those who completed both ADs and EPAs were more upfront and pragmatic about their outlook.

Death is a part of life. Lisa (68 years old) found it beneficial to talk openly about life and death around family gatherings and at the dinner table. She recalled her grandmother and mother who often said to her “it is no sin to die” and that it is important to embrace death as a part of life. Thus, she often shared stories about her family tree with her children and grandchildren. As a funeral celebrant, Lisa often took memorials and funerals of soldiers who did not have religious preferences. As if by happenstance, or by providence, while her mother was dying, her granddaughter was also being born at the same hospital, hence, a circle of life. Her husband Craig (74 years old) agreed with her about accepting and celebrating one’s mortality and mentioned the importance of having

rituals to offer some closure such as having “funerals” and “burials” for pets and farm animals, including chicks and mice.

Timing of death. While the timing of death was largely unknown, respondents acknowledged that they could contribute to providing comfort to the dying and their families. Barbara (73 years old) recounted that by the time they got to the hospital, her mother who was 97 year old had already died. Still, she knew that her uncle “had sat with her all that time during the day, so that was good”. For Shona (89 years old) spending time with her sister up to her final breath, and encouraging John “to go” were two of the cases which she considered *peaceful deaths*. Betty (67 years old) surmised that perhaps some people die in the early hours of the morning so as not to bother the rest of the family who were asleep. Greg (77 years old), a general practitioner who worked in Vanuatu for ten years, described a common local practice of self-willed death. He narrated that older folks who knew they were ready to die would summon their family members, bid goodbye, go to their rooms and in a few days would die. This topic is further examined under “Case 4” of the Narrative Analysis towards the end of the chapter.

The vocabulary respondents used to talk about death and dying and their frequencies were tabulated (see Table 4 below). These metaphors and expressions provide insight regarding their values, beliefs and responses to the end of life process.

Faith traditions and perspectives on end of life care. The themes on respondents’ beliefs on end of life care were quite sparse at first and became more apparent in a non-linear fashion throughout the data collection process. These included the following:

Sense of contentment. Many of the respondents viewed God as the final arbiter between life and death. As the oldest participant, Shona (89 years old) construed, God is the life giver and “you’ll go when God says it’s time for you to go”. Rosie (68 years old) held that those who had faith enjoyed a sense of contentment and hence, welcomed death as a transition.

Afterlife. Earl (74 years old) was hopeful that when his time comes, he would be going to heaven, in the afterlife. He was more concerned however, for his wife, Christine (73 years old) saying “who will look after her” if he died first?

Death preferred to being a “vegetable”. A majority of respondents preferred death rather than being in a vegetative state largely due to the fear of losing their cognition. Some hated the thought of being a burden to loved ones by losing control of bodily functions and losing their dignity.

Need for religious rituals. Fortunately, the church is replete with rituals and provided a community of faith. The Roman Catholics in the group cited the benefits of being in a Catholic rest home including access to priests who said masses and gave the sacraments, presence of nuns and their singing, and a religious preparation for one’s passing. Two widows from a Protestant church, Elizabeth (82 years old) and Shona (89 years old) found the spiritual and grief support they needed from the congregation. One of the church rooms was even named after Elizabeth’s late husband. She reminisced, “our church family is always there to lend support... especially at the time when Johann and my mother died, the church family were very much a part of us”. Interestingly, when the funeral director offered her bereavement support, she declined and said, “I’m fine because I have my church supporting me”.

Prayers and medications go together. Elizabeth and Shona signed up for volunteer work through “Meals on Wheels” and with choirs who sang in nursing homes. Shona valued the importance of faith and action. Having been a registered nurse, she maintained that prayers and medications go together.

Preference to die at home. As indicated earlier, several respondents preferred to die at home rather than in a rest home. One obvious reason was the dislike for the latter. The other reason was the strong familiarity and memories of their own homes.

Sense of fear. Christina (73 years old) suggested her own uncertainties and sense of fear with regard to dying: can the pain be managed? How long will the process last? What about the other unknowns?

Question Two: what do they consider the benefits and disadvantages to advance care planning?

Benefits of Advance Directives

These benefits were shared by eleven respondents, six completed their advance directives and/or enduring powers of attorney.

Help improve communication. ADs can be a tool for discussing family wishes and values for end of life care. Earl (74 years old) was quite practical when he said that it was better *knowing than guessing* because the former can help clarify conflicts among family members.

In their family tradition, Craig (74 years old) and Lisa (68 years old) talked openly about life and death. They also emphasized the importance of including the children in the discussion of health care options when facing a major health care crisis, and preferences for funeral and burial. A more detailed investigation of their family conversations on death and dying is found under Case 3 of the Narrative Analysis later in the chapter.

Glenn (72 years old) regretted that his family did not have such conversations prior to his mother's illness. His mother's health deteriorated until one day the family "virtually had no option" but to place her in a nursing home. Unfortunately, she was very unhappy with the strange environment. She quickly became depressed and died within two weeks. He also stressed the importance of communicating ones wishes before the "mind goes downhill".

Not be a burden to others. ADs can help take away the burden from loved ones and children. Gina (67 years old) narrated that "it is not fair to burden them with guilt". She completed an EPA and is interested in writing an AD because of her conversations with her children regarding palliative care and dying with dignity.

ADs can also provide guidelines to the family as in the case of removing life support. Greg (77 years old) and Barbara (73 years old) cited a cousin who was undergoing a heavy decision to "pull the plug" on her husband. She felt guilty because she they had not talked about such a scenario and felt somewhat responsible at the thought of shortening his life. Greg himself a general practitioner, added that perhaps the medical

staff had been remiss in providing adequate medical advice concerning palliative care. He felt that the staff needed to provide support for removal of life support if it is medically indicated.

Help plan ahead. Advance care planning can help one gain some sense of control and empowerment. Craig (74 years old) likened it to having travel or life insurance. Nowadays, it is practical to plan one's holiday travel with adequate coverage in case of accidents or emergencies.

When her father died, Lyn (75 years old) felt responsible for her mother, who became completely lost on doing the day to day household management. Her father did "everything" and Lyn helped her mother find where things were stored, pay the bills, and care for their property. This left Lyn resentful of her mother for having a dependent personality but strengthened her own resolve to plan for future contingencies. With the sudden death of her husband, she sought legal counsel in drafting an EPA and AD. Her independent streak helped her plan for future accommodation and health care needs. Lyn said:

You've got to think ahead if you possibly can... that's why I shifted to the village I'm in when I was left on my own so that I've got security. I've got a wee house... but there are apartments there so that I could shift into a smaller apartment... there's hospital care, there's a rest home care, there's a dementia room...

Lyn's optimistic outlook and habit of planning ahead is further explored under Case 1 of the Narrative Analysis section towards the end of the chapter.

Help ascertain treatment options. ADs usually include pain relief and comfort measures at the end of life. Greg (77 years old) completed both AD and EPA and hoped for a balance between pain medications and mental alertness. If he were dying, he would wish that his pain will be managed but not to the point of losing his cognitive abilities. Greg's treatment preferences are further considered in Case 4 of the Narrative Analysis section towards the end of the chapter. Paul (65 years old) who neither had an AD nor EPA desired to avoid a prolonged dying process. "I've actually never thought too much about that. But I certainly don't want to be left in a state where I'd be a vegetable... I absolutely wouldn't want to be in that". Several stated that they did not want heroic interventions nor their hearts resuscitated if they were in a terminal condition. They were clear about wanting adequate pain relief and preferred natural death.

Nevertheless, many in the Roman Catholic group were adamant about continued artificial feeding and hydration. Luke (73 years old) and Pene (73 years old) exclaimed, “no one should die of thirst or hunger”. In fact, they felt that stopping this intervention was considered euthanasia which was tantamount to murder. They quickly added that euthanasia and abortion were held on the same level because both actions destroyed lives. The Protestant respondents did not bring up this interpretation although they were mostly against euthanasia and/or assisted suicide. However, at least one respondent, Gina (67 years old) from an unknown denomination expressed willingness to pursue assisted suicide if she was dying with intractable pain, dependent on others, had no dignity, lacked control of bodily functions or if she was diagnosed with Alzheimer’s disease. Another respondent expressed sympathy with her position except she was keenly aware of legal barriers to euthanasia in New Zealand.

Help promote organ donation. Three of the respondents expressed interest in organ donation, that is, if “any of our bits and pieces” can still be viable to help others. These may include corneas, hair and other tissues. They rightly noted that this preference can be indicated on their driver licenses. Nevertheless, they raised two concerns: firstly, the family can override potential donor’s request, hence, the need for prior discussions and clear arrangements. Secondly, one respondent half-jokingly wanted to make sure that the organ donor team do not perform organ retrieval before they die. Some practitioners and consumers in the U.S. have protested the practice of donation after cardiac death (DACD) citing ethical concerns such as informed consent, conflict of interest, and determination of death --- whether the irreversible cessation of the cardio-pulmonary function has been ascertained prior to the harvesting of organs (Booth, 2008).

Disadvantages of Advance Directives

Three respondents who neither had an AD or EPA shared the following key perspectives. These provided insights regarding their resistances to the concept of advance care planning.

Limitations of ADs. In an era of rapidly changing health care technologies and scarcity of resources, ADs are not foolproof. Rosie (68 years old) commented that it is not possible to capture all treatment options. During the interview, she asked “how does one go about thinking of all the right questions through to make this a sensible document?”

Vince (79 years old) brought up the concern that if ADs are binding, what happens if someone changes his or her mind? At the outset, the answer is simple: one could just void the document and create a new one. However, the possibility of having two different written ADs may also raise other issues such as mental capacity at the time the documents were prepared. Additionally, different oral ADs may complicate a problem when there are conflicting treatment preferences.

Communication difficulties. Human communication is often quite complex. There are verbal, non-verbal, written and unwritten forms of communication, and not the least are societal expectations. Even families who have lived together for decades, life-long friends and certainly health care providers may misunderstand the patient's wishes in regard to end of life care. Earl (74 years old) surmised:

I think there would be cases where somebody always thinks that they know better than somebody else and their idea is different totally from the person and that they want to have their directives their way of dealing with the situation as 'the way.' And it may not be that they want to keep them alive for much longer.

Storage. Another disadvantage respondents mentioned deals with the storage issue, which impacts the timing when life sustaining interventions are applied. For instance, hospice patient "Aunt May" may be given CPR by the paramedics even though she has an AD and a DNR because her AD document could not be found at the time she was having cardiac arrest. So some questions regarding storage came to mind such as: *who will keep the document? Where can these be found? How do you access ADs when you are in the Accident and Emergency Department? Are these documents portable so that they follow the patient from the rest home to the acute care setting or to another region/country?*

Question Three: What were their reasons for completing or not completing an advance directive?

Reasons for AD completion

Those who completed their directives cited four reasons: death of a spouse, concern for family, autonomy, and independent personality.

Death of a spouse. One of the six who completed an AD and EPA was Lyn (75 years old) who only began considering her future health care plans after the death of her spouse. Elizabeth (82 years old) and Shona (89 years old) sought legal advice after the deaths of their husbands and decided to draw up their EPAs. While not having an AD or EPA, Grace (73 years old), another widow acquired her own funeral plan after her husband died. She proudly stated in the group that the plan had been paid for and that she wanted her daughters to have a party after she dies.

Concern for family/survivors. Craig's (74 years old) concern for his family was his reason for completing his AD. He used the analogy of their preparations when they travel --- these included planning schedules and activities and purchasing travel insurance so in the event they meet an accident, their children will be cared for. Thus, planning ahead for medical care and funeral would keep his family from worrying about his wishes at the end of life.

Autonomy --- sense of control and empowerment. Respondents mentioned that having an AD increased their autonomy amidst a scenario of uncertainty and death. Being aware of some choices and taking part in the decision making process provided a sense of control and empowerment. Greg (77 years old) and Barbara (73 years old) designated one of their sons to be their attorney for legal and property matters, and a daughter to be their health care representative in case they became mentally incompetent.

Organised and independent personality. Having been a school teacher for some 35 years, Lyn (75 years old) prepared her lesson plans ahead of time and was comfortable making decisions. Betty (67 years old) took the reins of their family business and learned to stand on her own in spite of family and organisational challenges. A more detailed investigation into Betty's choice of an independent lifestyle is found in Case 2 under Narrative Analysis towards the end of this chapter. Lisa (68 years old) had been a strong community advocate particularly with women and migrant workers.

Reasons for not completing an AD

The reasons respondents expressed for not completing ADs were more subtle and no one voiced strong opposition to the concept. There seemed to be more uneasiness, lack

of information and lack of “buy in”. At least one respondent, though, was concerned that ADs may be used to shorten life.

Fear of the unknown. Lyn (75 years old) suggested that perhaps the fear of not knowing the circumstances at life’s end as well as the mystery of the dying process itself kept people from engaging in future health care planning.

Avoidance. A few respondents quoted the lines of the song from Fame (1980): “I’m going to live forever...” which begged the question of one’s mortality. Peter (87 years old) relayed his rationale in the form of: “I love my house and veggie garden” --- and resisted Lyn’s (75 years old) idea of considering a smaller retirement unit, and if needed, an assisted living or long term care. Then there was one who hinted that he would think about it when he was really sick.

Family expectations. With most of the respondents living locally and having family and friends in the community, there was a prevailing expectation such as: “My family is going to take care of me when the time comes and they’ll make the right decision.” This was voiced by Vince (79 years old) who did not see a need for an AD because his family understands his pragmatic views on life and death. After all, “once your life has come to an end, it’s kaput, it’s finished you see... at least to my way of thinking”.

Faith in the providers. A common notion was expressed in the saying, “the doctors know what is best”. Elizabeth (82 years old) declared: “I believe God gives the medical people the ability and we must go along with that”.

Difficulty in ascertaining all future options. Vince (79 years old) queried: “Medical technologies are rapidly changing... who knows in the future, there might be more effective interventions?”

Lack of information about ADs. Quite a few said they were unfamiliar with the term “Advance Directives”. Earl (74 years old) suggested; “... there needs to be more education about it. People don’t think about it until they are faced with reality”.

May be used to shorten life. At least one respondent mentioned that it “...gets frightening to know what these options are” (Faith, 75 years old) ... “I think we are slowly being surrounded by a culture of death. Euthanasia is creeping in as a very sensible thing to think about”.

Talking about death and dying: content analysis

Table 4 below illustrates the summative analysis (Hsieh and Shannon, 2005) of the themes that describe the respondents’ vocabulary on death and dying. The themes are arranged from most to least frequently used and the sample expressions and metaphors are the respondents words “in vivo” or expressed in their natural setting. The frequencies of the descriptions were manually counted using the “Find” function, in Microsoft Word.

Table 4 Talking about death and dying

Themes	Frequency	Descriptions (in vivo)
Gentle process	56	“It’s time to go” “let go” “go to the other side” “pass away” “sleep”
Unpleasant process	33	“prolonging death” “painful death”
Fear of losing cognition	14	“vegetative state” “lose your marbles”
Quick and pain-free	12	“switch off” “go out like a light” “good pain relief”
Cessation of life	11	“end” “terminal”
Do not resuscitate	11	“No resuscitation”
Beyond ones control	10	“God will take us” “euthanasia”
Stopping treatment	5	“Turn off life support” “pull the plug” When you “lose your dignity”

The words “death,” “die,” and “dying” were used eighty times and “funeral” was used seventeen times. At least one respondent mentioned that her funeral plan was already paid off even though she did not have an AD or EPA. The term, “hospice” was only used 3 times and “palliative care” was used 1 time. Quite interestingly, no one mentioned the phrase, “end of life care” except the interviewer.

The theme of death as a “gentle process” (used 56 times) was illustrated vividly by the oldest respondent, Shona (89 years old), a former nurse in labour and delivery. With her thick Scottish accent, she recalled two accounts of what she considered a “peaceful death”. One was that of her sister, whom Shona visited during her final moments. “She wasn’t conscious or anything but I was with her all the way... every breath she took... And it just suddenly hit me --- she’s gone.” For Shona it was a bitter sweet experience: sadness that her sister was dead, but also feeling privileged to be there until her last breath. In another case, Shona went to see a male friend while he lay unconscious in the rest home. When no one else was in the room, she drew near John’s ear and whispered, “time to go, John.” He died later that night. She believed that being there, being present and providing assurance helped John during his dying moments. At this stage in her life, Shona assessed that she would not prefer to have cardio-pulmonary resuscitation (CPR) under any circumstances if her heart stops. Amongst other respondents, there was an active sense of “it’s time to go” and a fatalistic sense of “when it’s your time to go, then go,” to a religious sense of “when God says it’s time, then you go” which is close to the theme “beyond one’s control”.

Death as an “unpleasant process” (used 33 times) referred to the untreated pain associated with the long protracted dying process. Thus, there was a strong preference for a “quick and pain free” death (used 12 times). Closely related to the physical suffering is the fear of losing one’s mental abilities (used 14 times). This fear was so pronounced that several expressed preference for “do not resuscitate” (used 11 times) order if they will only end up in a vegetative state which means total dependence on others or machines and without dignity.

Death as “beyond ones control” was used in the sense of God (external benevolent force) as “taking us” (used 5 times). There was also a sense of providers (external malevolent force) causing deaths through euthanasia (used 2 times) and abortion (used 3 times). The latter view deemed that patients had no choice or control. Understandably,

Gina (67 years old) the lone voice for assisted suicide disagreed and argued that it was actually “within one’s control” to choose death on one’s own terms. Expanding on the notion regarding who is in control, the physician Greg (77 years old) shared the practice of “self-willed death” in Vanuatu. While this practice may be foreign to western thinking, it did have the advantage of saying goodbye to family, closure and perhaps even timing.

None of the respondents contended that “stopping treatment” (used 5 times) in the sense of turning off the respirator or “pulling the plug” was considered euthanasia or assisted suicide. Finally, respondents were in agreement that death meant “cessation of life” (used 11 times) and for some, *home* was the “preferred place of death” (used 4 times).

Narrative Analysis

To obtain a more in-depth investigation of the reasons why the six respondents completed both the AD and the EPA, I have adapted a simplified Riessman’s (2008, p. 92) and Wells’ (2011, p. 64) use of Labov’s (1982) functions of clauses (see Table 5 below) and Gee’s (1991) units of discourse. As with the respondents, pseudonyms were also used to hide the identities of their family members.

Table 5 Functionality of Clauses

AB = abstract	summarizes the narrative
OR= Orientation	provides the setting, such as time, place, situation, respondents
CA = Complicating action	describes what happened, sequence of actions, turning point
EV= Evaluation	indicates narrator’s commentary on complicating action
RE= Resolution	resolves plot; tells what finally happened
Coda	ends the story; returns listener to the present

In assessing the functions of clauses, the themes were grouped as stanzas and the interviewer’s presence had been omitted. The latter proved to be quite challenging because without the interviewer’s questions, there will be obvious gaps in the dialogue. For example, in Case 1, line 24 below, Lyn was actually responding to the question “how many years were you a teacher?” And that she prepared her lesson plans diligently, hence,

on line 25, she replied “yes, always planned ahead”. The use of ellipsis may alert the reader that some of the conversations had been deleted to make the case more concise. I also added implied words in parenthesis based on the context of our conversation.

Case 1 highlighted how completing ADs and EPAs were consistent with her habit of planning ahead.

Case 1: Planning ahead

Lyn (widow, 75 years old)

Summary of case. Lyn is a tall, lovely woman with short hair who looks prim and proper and very professional. She relates well with her peers, speaks with a fast kiwi accent and has been quite active in her community, including singing in two choirs. She was part of the focus group composed of four respondents whom I met on 26th June at a local church. Lyn struck me then as someone who was confident and knew her health care preferences. In fact, she was the first person I had met in Dunedin who completed both advance directives and enduring power of attorney. So I decided to conduct a follow up interview with her on 3rd July to investigate how she came to make those decisions. I started off by saying to Lyn “...I’m really curious about how you were able to come to a point in your life where you know what you want and you’ve taken action and you’ve planned... can you say more about that?” Lyn’s units of discourse (Gee, 1991) may be deconstructed as follows.

Organised person

Stanza 1

- 01 ...yes it’s most probably, it’s me
02 it’s my personality
03 I’ve always been an organised person

Planning ahead

Stanza 2

- 04 and so I have always planned
05 when I was teaching and everything,
06 I’ve always planned
07 I’ve always looked ahead
08 and planned I guess all my life
09 It’s just me

My mother didn’t plan ahead

Stanza 3

10 and I guess I had a mother who *didn't* (her emphasis)
11 and she irritated me because she *didn't* (her emphasis)

Determination

Stanza 4

12 And I think it made me more determined
13 that I would... yes, do this, yes

Parenthood

Stanza 5

14 There's different things we learn from our parents
15 some good
16 and some that we think we would do that
17 and other things we think we would --- No!

Children

Stanza 6

18 And my children would feel the same about me
19 And some things that they'll follow
20 and think that mum's good
21 and other things that they'll think
22 I don't know why she did that... I would never do that
23 This is human nature isn't it?

Teaching

Stanza 7

24 (*I've been teaching*) ...thirty five (years) or something

Planning ahead

Coda

25 yes, (*I've*) always planned ahead

Lyn cited several reasons why she liked to plan ahead. It was her personality to be organised (02, 03). This trait was evidenced in her teaching career and general outlook in life. Having been a teacher for thirty five years, she prepared her lessons in advance. She had been forward looking and credits her optimistic outlook as just a part of her personality (09). During the focus group which was held a week prior to this interview, Lyn mentioned that her father did "everything at home". Unfortunately, Lyn recounted that when he died, her mother who was dependent upon him was completely lost and devastated. Moreover, Lyn resented the fact that her mother expected her to pick up the pieces and take control of the affairs at home. Lyn used the verb "irritated" and emphasized with the tone in her voice when she said, "**didn't**" (10, 11), that is, her mother didn't plan ahead to take care of their home, finances and others. As a result, Lyn

emphasized during the focus group that she did not want to be a burden to her adult children.

(Later during the interview)

Advance Directives

Resuscitation

Stanza 8

25 ...if it was just a little heart problem that can be dealt with
26 then it's no (i.e. *resuscitation*)
27 But say, I was in a bad accident and it's really... (*bad*)
28 well, then I don't want any resuscitation

Advance serious illness

Stanza 9

29 ... I just want pain relief

People with advance serious illness

Stanza 10

30 I've thought and I've seen other people
31 and it makes you think
32 and I didn't want to be like some of the people I've seen (i.e. *in rest homes*)
33 and friends you know
34 I have one friend in particular, he took a stroke
35 He had been a very active person as well,
36 and he was so unhappy
37 and it was so awful to see him so unhappy
38 and so I thought... it's very difficult

Help from daughter

Stanza 11

39 Once Henry died, of course I had to change my will
40 It must have been at that stage
41 I was talking with my youngest daughter, Sandra
42 she came with me in talking with the lawyer
43 Sandra was a trained nurse
44 She knows a few things too.
45 And then we just discussed it
46 and I made it quite clear to my lawyer at that time
47 that I knew then sort of what I wanted or didn't want

Barriers to planning ahead

Stanza 12

48 ...fear of the unknown, not willing to take that step

49 into thinking of the things that could be....
50 ...I think that this is something that worries people
51 the monetary side of it
52 ahmm... and I do think of it
53 Well some of them refuse to think that something will happen
54 They go along blissfully
55 that they're both going to be there forever
56 And it just doesn't work out like that

Unplanned crisis

Stanza 13

57 You know... mind you, I wouldn't say
58 I could do all of that in detail
59 until I lost Henry
60 Cuz I hadn't thought about it either
61 I didn't expect him to suddenly drop dead

Choosing to change

Stanza 14

62 So you change because of circumstances
63 you have to change
64 And I decided, I thought
65 well, am I going to be a moaning miserable person
66 feeling sorry for myself
67 or am I going to get up there and go
68 and make the most of life

Get up and go

Stanza 15

69 And I've decided to get up and go

Having known other people with advanced illness in rest homes added to her reason why advance planning was necessary (stanza 10). This may include downsizing, selling their home and choosing better rest home facilities. Lyn's pivotal experience was the death of her husband. Fortunately, her daughter (stanza 11), a nurse, was there for her. Her daughter introduced a lawyer who assisted Lyn in updating her will an enduring power of attorney and advance directive. She gave copies of these instructions to her doctor and children stipulating that she did not want resuscitation in case she developed an advance serious illness. Additionally, she wanted to be pain free. Lyn believed that fear of the unknown, monetary worries and denial are three of the barriers to advance care planning.

During the focus group meeting, she shared with the group that she had a positive outlook and making decisions gave her a sense of control.

Another way of viewing Lyn's trait of planning ahead is by ascertaining the functionality of the clauses (Labov, 1991, Riessman, 2008). In Table 6 below, for every Complicating Action (CA), Lyn responded with an Evaluation (EV) or commentary of the preceding section. It was evident that Lyn's personality, work experience and lessons from her parents have helped her plan ahead for contingencies. In spite of a major unplanned crisis, namely, the sudden death of her husband, she learnt to receive help from her family, particularly her daughter. These experiences, as well as her firsthand knowledge of people in rest homes have contributed to shaping her decision to plan for eventualities such as pain relief, no resuscitation and end of life care. This vignette closed with her Resolution (RE), "And I've decided to get up and go" which captures much of who she is as a person.

Table 6 Lyn's Function of Clauses

Function	Clauses
Abstract (AB)	03 I've always been an organised person 04 and so I have always planned... (ahead)
Orientation (OR)	05 when I was teaching and everything, 06 I've always planned 07 I've always looked ahead
Complicating Action (CA)	10 and I guess I had a mother who <i>didn't</i> (her emphasis) 11 and she irritated me because she <i>didn't</i> (her emphasis)
Evaluation (EV)	14 There's different things we learn from our parents 15 some good, 16 and some that we think we would do that 17 and other things we think we would --- No!
Complicating Action (CA)	25 ...if it was just a little heart problem that can be dealt with 26 then it's no (<i>resuscitation</i>) 27 But say, I was in a bad accident and it's really... (<i>bad</i>) 28 well, then I don't want any resuscitation 29 ... I just want pain relief
Evaluation (EV)	32 and I didn't want to be like some of the people I've seen (i.e. <i>in rest homes</i>)
Complicating Action (CA)	39 ...Once Henry died, of course I had to change my will

Evaluation (EV)	41 42 43 46 47	I was talking with my youngest daughter, Sandra she came with me in talking with the lawyer Sandra was a trained nurse ...and I made it quite clear to my lawyer at that time that I knew then sort of what I wanted or didn't want.
Evaluation (EV)	62 63 64 65 66 67 68	...So you change because of circumstances you have to change And I decided, I thought well, am I going to be a moaning miserable person feeling sorry for myself or am I going to get up there and go and make the most of life
Resolution (RE)	69	And I've decided to get up and go

Case 2: Independence

Betty (widow, 67 years old)

Summary of case. The following is a vignette from my follow up interview with Betty on the 14th of October at the city centre. She took part in the focus group held on 6th July. She is a petite introverted woman who enjoys her independence and privacy. She has been joining a group of like-minded folks for lunch on Wednesdays at noon. Betty is originally from Australia but has been living in Dunedin for over 30 years after marrying a kiwi. Unfortunately, her late husband died after a long bout with cancer. Despite not having any blood relative in New Zealand, she considers Dunedin her home and enjoys living alone in her house and gardening.

The units of Betty's discourse (Gee, 1991) may be deconstructed as follows.

On my own

Stanza 1

- 01 I think that being on my own,
02 not having my own family,
03 the step children will be the ones
04 who will be involved in my estate.

Planning to manage business

Stanza 2

05 And I'd just like to make things as easy
06 and for everything to run as smoothly as possible.

Leon put things in order

Stanza 3

07 After losing Leon,
08 I found that he had everything in order.
09 He was aware that his time was limited
10 so he put everything in order.
11 He did do that.

Difficulties with managing the business

Stanza 4

12 There were a number of things that were very very difficult.
13 Ahh to finalise probably and ahh...
14 there's not a lot of cooperation out there from people.
15 I think that when you lose somebody
16 the thing is, I suppose, is to make sure
17 that there were no other worries or concerns
18 and to get everything settled and finalised.
19 And it's a worry to have all of these threads still hanging...
20 banking people, people who ahh... who just don't realise
21 that it is a worry to the person left behind.

Managing the household accounts

Stanza 5

21 And ahm... Leon and I shared to some degree
22 the running of the household
23 paying accounts and doing those sorts of things.
24 It wasn't as if I wasn't involved with that
25 and didn't know what I was doing.
26 Ahmm but it was still very difficult.
27 So in my case, I would like things to be as smoothly as I possibly can.
(Later during the interview)

Valued independence

Coda

28 I think because I want to remain independent,
29 make my own choices
30 I think that being on my own,
31 there are a lot of people (*think?*) that they know better than I do
32 to how I should live my life.

Pressure from family

Stanza 6

33 And there's a lot of pressure sometimes.
34 And after Leon died,
35 there was a little pressure from the family
36 ...well meant I think, but they weren't walking in my shoes.
37 And so I felt that I had to take control. (pause)

Valuing independence

Coda

38 So that's the main thing --- the independence ,
39 to make sure that I am well cared for
40 ahm... but completely independent.

Advance directives

Stanza 7

41 I have signed a document
42 so that I don't want my life prolonged
43 if ah... if anything like that occurs.

Proxy decision-maker

Stanza 8

44 My stepdaughter, her training was in nursing
45 and also ah... in counselling.
46 And Pat and I are very very close
47 and I have the utmost confidence
48 that she would make the right decisions
49 when the time came,
50 we have spoken about this,
51 we've talked about things.
52 Basically I would leave it to her.

No resuscitation

Stanza 9

53 She knows that if it were a major illness
54 that I wouldn't want to be resuscitated.

Betty's loss of her husband intensified her being "on her own" (Stanza 1). They do not have any children together, although he has some from a previous marriage. His untimely death also meant difficulties in the management of their business. While Leon "put things in order" (Stanza 3), yet there was not a lot of cooperation out there from the "people" (14). She did not specify who these people are. Without going into details, she mentioned the banks (20), probably from business loans. But there was also pressure from the family (Stanza 6). She began the section with "there's a *lot* of pressure sometimes (33)

... and “there was a *little* pressure from the family” (35). It may be Betty’s politeness that made her change her modifier from “a lot of pressure” to “little pressure” as a way of protecting Leon’s family. Nevertheless, it seemed that she was also hinting some family conflicts in the previous section, “...there are a lot of people (*who think?*) that they know better than I do (31)... to how I should live my life (32). She seemed conflicted by saying that their comments were well meant (36) but retorts, “they (family) weren’t walking in my shoes”. In the end, she took charge: “I had to take control” (37). Understandably, she reiterated her emphasis on being independent (Coda). The Evaluations on Table 7 below reveal how she treasured her independence. She made plans for her future care by signing a document (advance directives) which stipulated that she did not want her life prolonged if she developed an advanced illness. Fortunately, amidst family tensions, she trusted Pat, her step daughter, and in fact has designated her to be the proxy decision-maker (Evaluation). She expressed confidence in Pat to make the right decision when the time comes (Resolution).

Betty’s function of clauses (Labov, 1991; Reissman, 2008) may be classified on Table 7 below.

Table 7 Betty’s Function of Clauses

Function	Clauses
Abstract (AB)	01 I think that being on my own, 02 not having my own family...
Orientation (OR)	07 After losing Leon, 08 I found that he had everything in order.
Complicating Action (CA)	12 There were a number of things that were very very difficult. 14 ...there’s not a lot of cooperation out there from people. 18 ...and to get everything settled and finalised. 19 And it s a worry to have all of these threads still hanging... 20 banking people, people who ahh... who just don’t realise 21 that it is a worry to the person left behind.
Evaluation (EV)	28 I think because I want to remain independent, 29 make my own choices.... 35 ...there was a little pressure from the family 36 ...well meant I think, but they weren’t walking in my shoes. 37 And so I felt that I had to take control. (pause)
Evaluation	38 So that’s the main thing --- the independence ,

(EV)	39 40	to make sure that I am well cared for ahm... but completely independent.
Complicating Action (CA)	41 42 43	I have signed a document so that I don't want my life prolonged if ah... if anything like that occurs.
Evaluation (EV)	44 45 46 47 48 49 50 51	My stepdaughter, her training was in nursing and also ah... in counselling. And Pat and I are very very close and I have the utmost confidence that she would make the right decisions when the time came, we have spoken about this, we've talked about things.
Resolution (RE)	52	Basically I would leave it to her.

Case 3: Family conversations

Married couple: Lisa (68 years old) and Craig (74 years old)

Summary of case. This vignette was taken from the focus group held on the 6th of July, 12 noon at a centre in the city. We sat on folding chairs in a circle in a closed private room with an approximately 15 square-meter area. The panel heaters were on and the atmosphere was informal and relaxed. There were five respondents, three women and two men whose ages ranged from 67 to 74 years old. Three of them were neighbours, and two had served in the military. They all knew each other well and had been meeting informally at the centre for lunch on Wednesdays. The unit discourses from Lisa and Craig show how traditions such as open family conversations are passed on from one generation to another. Despite being retired, she performs various roles in the community --- she serves as a Justice of the Peace and a community advocate. She volunteers at the Red Cross, women's shelter and functions as a mediator as needed. Lisa is quite outspoken about her views and yet she is able to share her stories in a funny and disarming manner. The units of discourse (Gee, 1991) for Lisa and Craig may be deconstructed as follows.

Family conversations: Lisa's grandmother

Stanza 1

01 when she (*Lisa's grandmother*) was then very very old
02 (*she*) would say to me "don't worry, it is no sin to die..."

03 We were a family that talked about living and dying
04 and dying is part of life.
05 And so it (*dying*) was not hidden.... you just talk about it (*dying*).

Family conversations: Lisa's mother ***Stanza 2***

06 (*Lisa*): We have a family story when the kids were wee still,
07 they'd go up to mother and say
08 "are you going to die today granny?"
09 "No I don't think so".
10 "Alright, I'll stay" (*Lisa* laughs)

Family conversations: Lisa's family ***Stanza 3***

11 (*Lisa*): We just talk about it (*dying*)... I don't know.
12 It's just part of the whole family ethos.

Coda

Lisa's work as funeral celebrant for soldiers ***Stanza 4***

13 (*Lisa*): And I was the first independent funeral celebrant in Dunedin
14 Yeah. Because there was a need.
15 And particularly for a lot of soldiers who came back
16 who had no religious affiliation,
17 and said with great respect,
18 "I don't want to be done by the church when I die"
19 It was just part of living and dying.

Lisa's work as funeral celebrant for animals ***Stanza 5***

20 (*Lisa*): We had animals that died, chicks that died,
21 we had mice that died ...
22 we had funerals for everybody.
23 (*Craig*): Yeah! We had a number of plots all around the garden
24 where different animals were buried.
25 Some have crosses on them, some didn't ...
(Later during the focus group)

Family conversations: discuss end of life options ***Stanza 6***

26 (*Craig*): Like it or not, I think it should be discussed well
27 what the options are, well before the situation arises
28 so that you've got some background for your decisions.

Family conversations: discuss options with children ***Stanza 7***

29 (*Craig*): A whole number of people apart from your mother and father,

30 the children particularly, should be brought into the discussion
31 so that they are aware of the likelihood.

Family conversations: discuss value of planning ahead ***Stanza 8***

32 (Craig): With the way of flying and travel now,
33 you know, anything can happen.
34 We take out insurance when we fly...
35 we both fly together on the same plane.

Family conversations: discuss funeral plans ***Stanza 9***

36 (Craig): So all of a sudden the children are left with the decision to make
37 “What do we do? Where do they go? Where’s the funeral going to be?
38 Where will they be buried? My plot? Your plot?”

The units of discourse proved to be very similar to the function of clauses classification, hence, a summary of discourse in Table 8 was preferred. This presented their arguments in a simple, rational and profound manner. Lisa learnt early in life from her grandmother and mother who engaged them in conversations about living and dying. Lisa repeated the phrase, “it’s no sin to die” during the focus group. She in turn passed on such open discussions to her children. Furthermore, her work experience as an independent funeral celebrant provided a niche for non-religious soldiers who did not want to have a church funeral (Stanza 4). Interestingly, the juxtaposition of her next discourse about funerals for their animals (Stanza 5) provided a range of acceptance of death and rituals to extend beyond humankind.

Craig picked up where Lisa’s discourse ended and opined that end of life options ought to be discussed amongst families well before a crisis occurs. Instead of being shielded, the children needed to be included in these conversations (Stanza 6). Planning ahead may include such actions like purchasing flight insurance so that the children will not be burdened with the financial expenses in case of accidents. Similarly, conversations about funeral plans help children cope and prepare for such realities.

Table 8 Summary of Lisa and Craig’s discourse

Lisa	Lessons learned	Engaged in intergenerational conversations <ul style="list-style-type: none"> • Grandmother • Mother • Children
	Lessons applied	Provided funerals for soldiers Provided funerals for animals
Craig	Recommendations	<ul style="list-style-type: none"> • Discuss end of life options • Discuss options with children • Discuss reality of impermanence • Discuss funeral plans

Case 4: Preferences in end of life care

Married couple: Greg (77 years old) and Barbara (73 years old)

Summary of case. I interviewed Greg and Barbara at their home on a late Sunday afternoon in July. The three of us sat around the coffee table. Greg has worked as a general practitioner for a number of years. He is still associated with the World Health Organisation and takes those long flights to third world countries which are especially ravaged by malaria, HIV/AIDS and tuberculosis. When he is in Dunedin, he plays the organ at his church. Barbara is also active in church and is involved with the women’s group and missions. They have been strong advocates in the Zimbabwe outreach where their denomination has helped farmers acquire cows, dig up water wells and develop agricultural technology. Greg speaks in a slow monotone voice whereas Barbara is more animated and engaging. Nevertheless, as Greg narrates about their ten-year work experience in Vanuatu, he breaks down in tears as he remembers the islanders’ hospitality, warm welcome and lavish send-off gifts. Greg and Barbara’s units of discourse (Gee, 1991) may be deconstructed as follows.

Sense of mortality

Stanza 1

01 I think you can even reach the stage

02 no matter how positive you feel
03 that if it's time to go for whatever reason
04 you feel that there's not much point in living anymore

Weariness

Stanza 2

05 that it's such as struggle and I'm tired
06 ... and the effort required overwhelms me.

Anticipation

Stanza 3

07 and ah.. that's a decision I could anticipate making.
08 I've never felt that way (laughs)
09 but you see people reach that stage
10 and it's a decision when they reach that state
11 they usually die fairly soon.

Saying goodbye (Vanuatu)

Stanza 3

12 It's interesting when we were working in Vanuatu
13 ah.. part of the culture ... if an old person,
14 nothing wrong with them, decided they had lived long enough---
15 they'd sit down and tell their family goodbye.
16 Ahh... and they would... in a few weeks would die.
17 Because they didn't feel like they weren't of any use anymore
18 with much purpose in living.
19 Ahh... and that was good because their family and friends
20 would gather around and they would share their time---

Place of death (Vanuatu)

Stanza 4

21 another thing about their culture is that they are very critical of us
22 Pākehā who put old people at (rest) home.
23 They think that's disgusting ...
24 they think they should be looked after at home
25 with their family. They don't like that at all. (pause)

Putting up with pain

Stanza 5

26 (*Barbara*): ...yes, it's a different way of life.
27 It's all very well to sit here and pontificate.
28 Ahm... I've never had to put up with much in the way of pain.
29 And what would I be like if I might change altogether,
30 if ahm.. I had that kind of pain

31 that people live with for a long time.

32 Yeah. That might be quite different.

Pain management: all pain should be controlled

Stanza 6

33 (Greg): they say that all pain should be controlled

34 ah.. it's not always whether that's because the patient

35 hasn't sought medical attention when they should

36 or whether the doctor feels they have enough.

37 I don't know if it varies but

38 there would be a time if pain couldn't really be handled in any way.

Yes cognition, yes pain

Stanza 7

39 And you'd want relief somehow,

40 you would have the choice too

41 of remaining mentally alert with the pain

No cognition, no pain

Stanza 8

42 or having no pain and being severely mentally suppressed.

42 That all pain should be able to be controlled

43 but (muffled)...but at the sacrifice of less mental abilities.

44 So you really in effect become a vegetable.

Hope for a happy medium

Stanza 9

45 (Greg): I would hope that I could find a happy medium.

46 That I could put up or tolerate some degree of pain

47 and maintain mental alertness

48 but whether that's always possible

Some pain, some cognition

Coda

49 I'm not sure but probably it is.

Care at the end of life involves a realistic assessment of the symptoms that death is near. Greg distinguished between “feeling positive” (02) and accepting that “there’s not much point in living anymore” (04). He qualified this later when he cited the case in Vanuatu which is more of a self-willed death where some people have “decided they had lived long enough” (14). There is an attractive element to this practice because of the family support and closure having devoted time to say their goodbyes (15) at their homes. In a real sense, this practice may be the “real” natural way of dying without aggressive treatment. However, Greg sounded a bit fatalistic by saying immediately following:

“Because they didn’t feel like they weren’t of any use anymore with much purpose in living” (17-18). Caring for older people and place of death were contentious issues because of the islanders’ preference of caring for their loved ones at home. The Pākehā practice of placing older adults in rest homes may be construed as a failure to observe filial obligations especially to the revered vulnerable populations, and hence, considered “disgusting” (23).

In Table 9 below, Barbara chimed in (EV 26) and shifted the discussion to the subject of pain. This was despite no mention of pain by Greg among the elderly Vanuatu. Earlier in the interview, we did touch on the idea that generally kiwis were non-complainers. Barbara traced the early Scottish migrants to New Zealand who were accustomed to tough times in Scotland. She recalled that being tough is part of life. To this Greg added: “yes, tough times, harsh climate, hard work, poorly paid... struggled to survive a lot of the time... so they didn’t complain”. Greg observed in his medical practice that while patients varied with their perceptions of pain, by and large, older people would not complain as much and would even downplay it. So perhaps Barbara inferred that if the pain was reported as “high”, then it might realistically be more of “severely high” on the pain scale.

In the West, the issue of pain control pertains to the gold standard of end of life care (beneficence). As Greg puts it, “they say that all pain should be controlled” (CA 33). In fact, under treatment of pain among seniors who have a terminal illness can be considered elder abuse. Understandably, however, in some cultures, suffering may have a redemptive value such as, “no pain, no gain”. There is also the belief that pain medications cloud the mind and thus, interfere with conscious dying. But Greg’s request was worth considering: between suffering needlessly with cognition on one hand (41) or being a vegetable (44) on the other, a happy medium for him would be tolerating some pain but with mental cognition. He ended this section with a cautious optimism, “I’m not sure, but probably it is” (Coda 49).

Table 9 Greg and Barbara's Function of Clauses

Function	Clauses
AB	01 I think you can even reach the stage 10 ...and it's a decision when they reach that state 11 they usually die fairly soon.
OR	12 It's interesting when we were working in Vanuatu
CA	13 ... if an old person, 14 ... decided they had lived long enough--- 15 they'd sit down and tell their family goodbye. 16 ... and they would... in a few weeks would die
EV	19 Ahh... and that was good because their family and friends 20 would gather around and they would share their time ---
CA	21 another thing about their culture is that they are very critical of us 22 Pakeha who put old people at (rest) home.
EV	23 They think that's disgusting ... 24 they think they should be looked after at home 25 with their family.
EV	26 (<i>Barbara</i>): ...yes, it's a different way of life. 27 It's all very well to sit here and pontificate. 30 ...if ahm.. I had that kind of pain 32 ...Yeah. That might be quite different.
CA	33 (<i>Greg</i>): they say that all pain should be controlled 41 ...of remaining mentally alert with the pain 42 or having no pain and being severely mentally suppressed.
EV	45 I would hope that I could find a happy medium. 46 That I could put up or tolerate some degree of pain 47 and maintain mental alertness
Coda	48 but whether that's always possible 49 I'm not sure but probably it is.

Conclusion

The data provided an enormous wealth of information ranging from spontaneous findings such as much discomfort in talking about death and dying to intergenerational

conversations about the subject matter around the kitchen table. On Question One, it became apparent that rest homes were a gateway to conversations on death and dying. Respondents' faith perspectives included God as the giver of life and Divine Providence, belief in an afterlife, and need for religious rituals among others. On Question Two, the perceived benefits of ADs were some practical matters such as improved communication, not being a burden to others, planning ahead, and ascertaining treatment options. Among the disadvantages were the AD limitations, communication difficulties, and problems with storage. On Question Three, the reasons for AD completion were death of a spouse, concern for family/survivors, autonomy - sense of control and empowerment, and having an independent personality. The reasons for not completing an AD included the fear of the unknown, avoidance, family expectations, faith in providers, and lack of information. Their vocabulary on death and dying was quite revealing --- the theme "gentle process" (e.g. letting go) was used 56 times. The two top fears were dying in pain, hence, an "unpleasant process," and dying in an undignified manner by "losing cognition" and languishing in a vegetative state.

The six who completed both ADs and EPAs reasoned that they valued independence, engaged in family conversations about death and dying, planned ahead (especially for those who experienced the death of a spouse), and expressed treatment preferences such as adequate pain relief at the end of life.

CHAPTER 5

Discussion

This chapter includes sections on reflections and limitations, discussion of the salient findings, peer feedback and implications of the study. While some of the interpretations are clear and evident, others were considered with caution to ensure that multiple perspectives were taken into account.

Reflections on Methods: lessons and adjustments

As Creswell and Plano (2011) reiterate, research cannot be separated from the “researcher’s personal views and characterizations” (p. 210). The following section highlights reflections on the research process, insights gained and attempts to improve the data collection.

One of the lessons I learnt early on was the importance of persistence in arranging focus group meetings due to cancellations and changes of venue. I began my data collection in winter and it was not convenient for older people to be driving at night to meet in someone else’s home. So I met with respondents during the day either in their homes, a church centre or a cafe. There were also technical problems with the audio tape not working, and contending with background noises and interruptions.

During my first two interviews, a couple expressed some uneasiness with the topic of death, due to guilt over grief issues and unfamiliarity with ADs. I felt a little protective of them and did not want the tone to be depressing so I moved on to the next question whenever the conversation became too personal. I was tentative at times and we were often “dancing around the issues” but I reminded myself that my role was that of researcher, not grief counsellor.

On some occasions, I thought I came across rather too validating when I heard myself on the audio tape saying “right”, “yes” or agreeing too frequently with the respondents. I also struggled at first with whether I was “interviewing” versus “engaging” and it seemed I was asking more closed or leading questions.

During supervision, I was encouraged to cut down my introduction which was highly technical, and instead of explaining what ADs are, I just needed to stay focused on

respondents' concerns. Since I know much about ADs and have advocated for their use over the years, I do have a tendency to give information about their utility. After some practice, I became more aware of my own responses and limited my explanation of ADs during the actual interview. I stayed around after the session to help respondents with their questions and encouraged them to ask their doctors if they needed more information. I did get anxious when I asked a question and respondents just gave me a pause or blank stare. I would then begin rephrasing the question or providing other options which sounded more of multiple choice items. My supervisor suggested that I try asking "can you tell me about their pain control" instead of "was their pain control adequate?" The former was more open-ended and this invited them to share more of their story, whereas the latter solicited a 'yes' or 'no' response. Once they got into their narratives, however, I felt confident that I provided empathy, active listening and encouraged them to clarify concepts or share multiple perspectives. Another suggestion I received was to close the session with something like "what advice would you give to an older person who is dying?" This question allowed respondents to distance themselves from the topic and take on the role of advisor. I found this quite useful because it helped them co-create some alternative narratives to describe what they may want for their loved ones or themselves. Repeatedly, their common response was to improve communication of one's wishes with family and friends.

During later groups, I felt more at ease, less hurried and more patient to draw out respondents' narratives. Following Dean's (2001) idea of becoming "more informed not-knowers" (p. 628), I endeavoured to practice self-awareness, respectful questioning, attentive listening, curiosity, interest and caring.

Limitations of the study

As mentioned in the Methodology Chapter, this study was exploratory in nature and as such had several limitations. There was a small number of respondents ($N = 24$) which limited the generalisability of results. All respondents were European-New Zealanders. There were no Maori, Pacific Islanders or other ethnic minorities in the group. Other demographic data were not collected such as length of residence in the city, and length of membership or attendance with their local church. The EPAs were included only with reference to ADs and it was interesting to note that all the six who completed their ADs began by drafting their EPAs first. Although frequently brought up by respondents,

the issue of euthanasia and assisted suicide was not an aim of this study. Hence, the information was noted but not further explored. While there were five widows who participated, there were no known widowers in the groups. The prevailing assumption is that females live longer since nationally, non-Maori females in NZ can expect to live 83 years whereas non-Maori males have a life expectancy of 79 years (Statistics New Zealand, 2009). Microsoft Word was used to tally word usage and frequencies which is prone to more human error compared to newer computer software. Lastly, this project did not include mental health advance directives.

Key findings

The key findings discussed in the next section have been grouped into four topics: communication issues, family support, faith and faith community, and autonomy.

Communication Issues. There were notable difficulties and opportunities in communicating with respondents about advance directives. Similar themes from research Questions Two and Three were grouped together to highlight issues pertaining to conversations on death and dying.

Discomfort. A spontaneous finding showed that the first focus group and three couple respondents expressed discomfort in talking about the end of life care of their loved ones. Despite the fact that they were older adults and had experienced the loss family members, this topic seemed a bit too personal and intrusive. Many were uncomfortable in sharing these matters outside of family. Leigh Manson who is the Advance Care Planning Project Manager at Auckland District Health Board explained that generally as a population, “planning for end of life care and treatment is not done because we do not talk about it...” And unfortunately, clinicians themselves do not raise the subject matter either because they are not taught how to, or they perceive death as a failure (Manson, L. pers. comm.. 2012).

Rest homes. Nevertheless, having changed my initial question from death and dying to the topic of long term care, a second spontaneous finding revealed that stories of loved ones in rest homes were a gateway to start a conversation about ADs. Rest homes were safer topics to complain about or have an opinion for, and at least one step removed

from death and dying. All respondents had much to say about rest homes and their narratives contained strong emotional tones. Family members were often torn between the risks of allowing their parent(s) to live alone in their own homes versus the guilt of shifting them to a rest home.

Rest homes conjured up both negative and positive connotations. Negative views of certain rest homes came from the experiences of their loved ones, their own personal encounters and the complaints heard from others. These included a sense of isolation, confined spaces, lack of cleanliness, and the feeling of being institutionalised. Care had been adversely affected due to the high turnover of aged care workers which may be precipitated by low pay and work related stress. Both of these issues were drawn attention to by the Human Rights Commission's (2012) report on aged care workforce.

The positive stories on rest homes had to do with a sense of autonomy and a balance between privacy and community. Rest homes which were run by religious denominations were preferred by many because they valued the familiar church rituals, security and the convenience of living in close proximity. Others preferred a community house type of model where there were fewer number of people but had more opportunities for residents to be in community with one another. One major down side however, was the high cost of such units.

Other communication difficulties. The lack of information about ADs was evidenced by their unfamiliarity with the term. For those who were familiar but had not completed ADs, they raised the issue of rapid advances in medical technologies. So, the concern was expressed in the argument: why would one have to decide to forego life sustaining treatment today if sometime in the near future, new interventions might prove to be more effective? In contrast, some were concerned that the directives could shorten life which bordered on euthanasia. Fear of the unknown during and after death deterred respondents from talking about future health care planning. Thus, it seemed easier to avoid it until one became gravely ill.

To be sure, the complexities of human communication are numerous. Even families who have lived together for decades, life-long friends and certainly health care providers may misunderstand the patient's wishes in regard to end of life care as documented by the SUPPORT Study (Teno, et al., 1994).

ADs as a communication tool. On the other hand, those who completed ADs and EPAs insisted that the documents were good tools to communicate their future health care wishes. The common argument for ADs was to inform family and providers regarding their choices instead of keeping them in the dark. Accordingly, knowing their directives beforehand provided more clarity which hopefully would lessen future misunderstandings and conflicts among loved ones. The inclusion of the children and loved ones in the conversations was stressed several times to insure that they do not become a burden to the next generation. This may arise from families who were torn with end of life decision-making. Having written clear directives would hopefully lessen the guilt when the family realise that they are not responsible for “pulling the plug” because the respondents already their made prior health care decisions in consultation with their physicians. In fact, following their directives would be a good way of honouring them and their wishes. Another form of guilt may arise from the respondents themselves in the scenario where the family had to carry the costs of medical care and funeral. Hence, like life or disability insurance, ADs can be a means to communicate to loved ones a set of instructions in case they develop a terminal condition. Finally, all the known widow respondents indicated that they began their advance health care planning after the deaths of their husbands and after having had numerous conversations with their families. The loss of their loved ones heightened their own sense of mortality.

Strong local family support. One of the reasons for not completing ADs was the respondents’ expectation that their family would take care of them when they face a serious illness. Thus, there was no urgency to engage in future health care planning. At the outset, it was important to note that many Dunedinites have strong family ties in the region compared to a large metropolis like Auckland where more frequent family migration tend to occur. Local families are expected to assist in long term care placement and treatment decisions at the end of life. This expectation was aptly summarised by the conversation between Angela (74 years old) and Dan (77 years old) during a focus group:

Angela: “Do we have an enduring power of attorney?”

Dan: “No we don’t my love. I’ve got you in the meantime and you’ve got me.”

Eighty eight percent (21 out of 24) of the respondents affirmed that they had a next of kin living locally. Those who had EPAs all spoke of a family member who would make decisions for them in case of incompetence particularly with regard to property matters. The respondents who were in their eighties had EPAs but none of them had ADs. This

assumes that they have some financial resources to pass on to the next generation and may be an easier topic of conversation rather than end of life decisions. Alternatively, perhaps they just lacked information about advance directives. All who completed their EPAs had access to lawyers and were encouraged by their adult children to seek legal advice.

According to Marie Bennett, social worker from Age Concern Otago, the average costs for such service range from \$800 up (Bennett, M. pers. comm. 2011). Peter (87 years old) explained,

we're quite lucky because Apollo, our son-in-law is a lawyer, so he's taking care of things and I can trust him. We've gone through this and we've sorted it out. You know what I mean?

Family obligations. The respondents claimed that families had certain obligations in caring for their older relatives. Adult children usually help make decisions regarding the choice of a rest home or long term care for their parents. The phrase: "Be nice to your family because they get to choose your rest home" was often quoted. For instance, a couple invited their mother to live with them and built a "granny flat" for her. This arrangement proved to be beneficial for the entire household including the grandchildren. Respondents who lived alone in their own houses chose independent lifestyles who felt secure knowing that their adult children lived only a few minutes away. Families were expected to participate in treatment decisions in cases of incapacity and visit older relatives who are near the end of life.

Family conflicts. Family conflicts can often arise during a health crisis even amongst the most functional families. If the older patient had not clearly expressed his or her wishes, then end of life treatment decisions can be complicated and heart-wrenching. These questions may include: *does she want to be resuscitated if her heart stops? How long will we keep him on a ventilator? Isn't 'pulling the plug' the same as killing? If we remove the artificial feeding, wouldn't she die of starvation and dehydration?* Last, but not least is the response: *aren't we praying for a miracle?* An adult child who lives the farthest may have guilt issues and prefer to spend more time with the dying loved one. On the other hand, some of the family members who have been providing ongoing care may sense that their loved one is ready to die. Others may feel mixed emotions of holding on and letting go, intense pressure and, burn out. Due to these complexities, even those who had not yet completed their ADs or EPAs agreed that these directives make sense. Those

who drew up the documents reasoned that they wanted things to be as easy and smooth for their families as much as possible. They also reiterated that ADs needed to be explicit and written down.

Family conversations. Conversations on life and death were common among the six individuals who completed both ADs and EPAs. They exchanged stories about their departed loved ones and the life-changing lessons in regard to planning for contingencies. In reflecting upon the impermanence of life, one learnt from her grandmother and mother the phrase “it’s no sin to die”. She in turn passed this on to her children and grandchildren. They also observed rituals such as funerals for their pet dogs, cats and farm animals. A couple immersed their children in the local culture of a Pacific island including the common practice of self-willed death among many elders. These families found that engaging conversations on death and dying provided more open discussions and expressions on celebrations and grief.

Faith and faith community. The social value of faith, faith community and views about death are summarised below.

Faith and action. As part of their belief, respondents displayed a positive sense of volunteerism and involvement with the community. These were demonstrated through participation in choirs who sang in rest homes and reaching out to older people by volunteering with the “Meals and Wheels” programme. A former nurse insisted that prayers and medications were essentially two sides of the same coin. Hence, faith was not just an end, but rather, a means to actively participate in the treatment plan. This view was a contrast with other religious beliefs which depended on prayer alone. Rituals also offered meaningful activity and quality of life such as the sacrament of the sick, communion, anointing, fellowship as well as hymns and prayers.

Church as extended family. Nearly all of the respondents expressed the church as an extension of their family. Since Dunedin is a small city, regular church goes not only see each other on Sundays but during the week as they go to the mall or buy groceries. A case in point was the Roman Catholic respondents who attended morning mass once or twice a week and then going out together for tea afterwards. Hence, churches provided community and resources for face to face social networking. In regard to bereavement

support, three widows from the same Protestant church often appreciated the congregation's pastoral care. Frequent visits from the minister and members afforded connectedness and continuity.

Death as transition. Having faith in God provided a sense of contentment and assurance that there was a providential presence during the time of death and beyond. There was an assumption of an afterlife and death was viewed as a transition not the end. Thus, one could "let go" in a peaceful and gentle process. It did seem ironic though that during the initial sessions, up to a third of the respondents were uncomfortable in discussing death and dying. Moreover, only a few shared their thoughts about mortality. Perhaps the section, "Reasons for not completing an AD" above offer some understanding on people's resistances in talking about death and dying. Still, most of the respondents preferred dying quickly rather than languish in a vegetative state. This preference stemmed from the fear of being a burden to others particularly through loss of cognition. Two concerns were raised, namely, a sense of fear regarding adequate pain management and worry for the loved ones left behind.

Autonomy. This next section focuses on the six who completed both ADs and EPAs and maintained that autonomy was the main principle for their decisions. They cherished a sense of independence, planned ahead, and expressed treatment preferences if they developed a terminal condition.

Sense of independence. Two of the widows sought help and consulted with lawyers when their husbands died. They wanted to remain independent and not rely on their adult children. Both of their daughters were instrumental in helping them complete their ADs and EPAs. They worked through their grief, faced the banks and took control of the family business. For the two couples, the sense of independence was evident in their chosen professions, church and community involvement. They valued self-reliance and volunteerism such as playing the church organ and inviting members for soup in their homes. One had been serving as a long time advocate for women and promoting self-determination among new migrants. Another worked at the World Health Organisation (WHO) to seek better health policies for populations stricken with infectious diseases like malaria and HIV/AIDS.

Planning ahead. A retired school teacher attributed her habit of planning ahead to her personality and profession. She found this discipline enabled her to gain some control in crisis situations and not have to be reliant on others. Consequently, she made significant plans for her long term accommodation, health care and financial needs. Another took a pragmatic stance after her husband died and planned for contingencies that affected the viability of their family business. She considered options for her own personal and money management including drawing up an EPA and AD. A couple designated their daughter in New Zealand to be power of attorney for health care decisions and their son in Australia to be in charge of the financial decisions. This planning made sense in particular because the proxy decision maker needs to be contacted easily and preferably within close proximity in cases of emergencies. Another couple compared ADs and EPAs like buying flight insurance or funeral plans. They stressed that such plans ought to be discussed with the family beforehand not just during a health crisis but during everyday conversations at the dinner table.

Treatment preferences at the end of life. The six respondents expressed similar sentiments indicating that if they developed advanced terminal conditions, they preferred to be pain free, not be resuscitated, not be a burden to loved ones, and not be given medical interventions that would only prolong their dying. However, one did concede that if her husband were still alive, she may have had a different perspective.

In regard to pain, Kiwis are generally non-complainers. Some respondents referred to the early Scottish immigrants who braved through tough times, harsh winter climate and struggle for survival. Older adults tolerate pain and may even downplay it. While some cultures associate pain and suffering as having redemptive value, nevertheless, as a medical officer, Greg (77 years old) believed that all pain should be controlled. In his case, he preferred sufficient medications to control his pain but not to the extent of losing his cognition.

Most of the other eighteen respondents noted that while medical technologies can prolong life, they can also prolong suffering. They disliked the idea of extending quantity of life but sacrificing its quality.

The fear of losing cognition ranked extremely high on the list of conditions respondents feared which perhaps was second only to untreated pain. The phrase was used

in the context of being in a permanent and irreversible vegetative state and having to be dependent on others. In fact, some preferred death than get resuscitated and then vegetate. A part of this fear was a concern about developing dementia or as they put it, “losing one’s marbles”. This was related to the fear of being a burden on the family and sense of shame in losing bodily functions. All the respondents were familiar with rest homes and were aware how late stages of dementia could affect the care of their loved ones.

Stopping life sustaining treatment was permissible such as “turning off life support” or the expression “pulling the plug” if patients were actively dying of a terminal and irreversible condition. Naturally, there was a strong preference for a quick and pain-free death. Nobody favoured a long, protracted and painful dying. Besides good pain relief, one suggested that she would rather just “switch off” when her time came. In a similar vein, another expressed wanting to just “go out like a light” and die quickly.

With regard to artificial nutrition and hydration, members of the Roman Catholic focus group appeared to be conflicted regarding its appropriate use. While they preferred palliative and comfort care for the dying, yet they believed that removing artificial nutrition and hydration will cause more suffering through starvation and dehydration. This in turn may be interpreted as moving towards “euthanasia by omission”. John Paul II’s address (2004) may have contributed to this notion regarding the moral obligation to provide artificial feeding to those in a vegetative state. Medical ethicists insist that in contrast with food and water administered orally, artificial nutrition and hydration are considered medical treatment and may be discontinued if the burdens outweigh the benefits (Fine, 2006). As well, Jonsen, Siegler and Winslade (2006) claim that there is no ethical distinction between withholding and withdrawing feeding tubes for the terminally ill. Therefore, while the dying may live longer, continuous artificial nutrition and hydration may actually cause more harm and suffering due to retention of fluids, increased pain levels and risk of infection (Casarett, Kapo and Caplan, 2005). To be sure, it is vital to offer palliative care including pain management, ice chips for dry mouth, skin care, bed positioning, and complementary therapies such as music and aromatherapy.

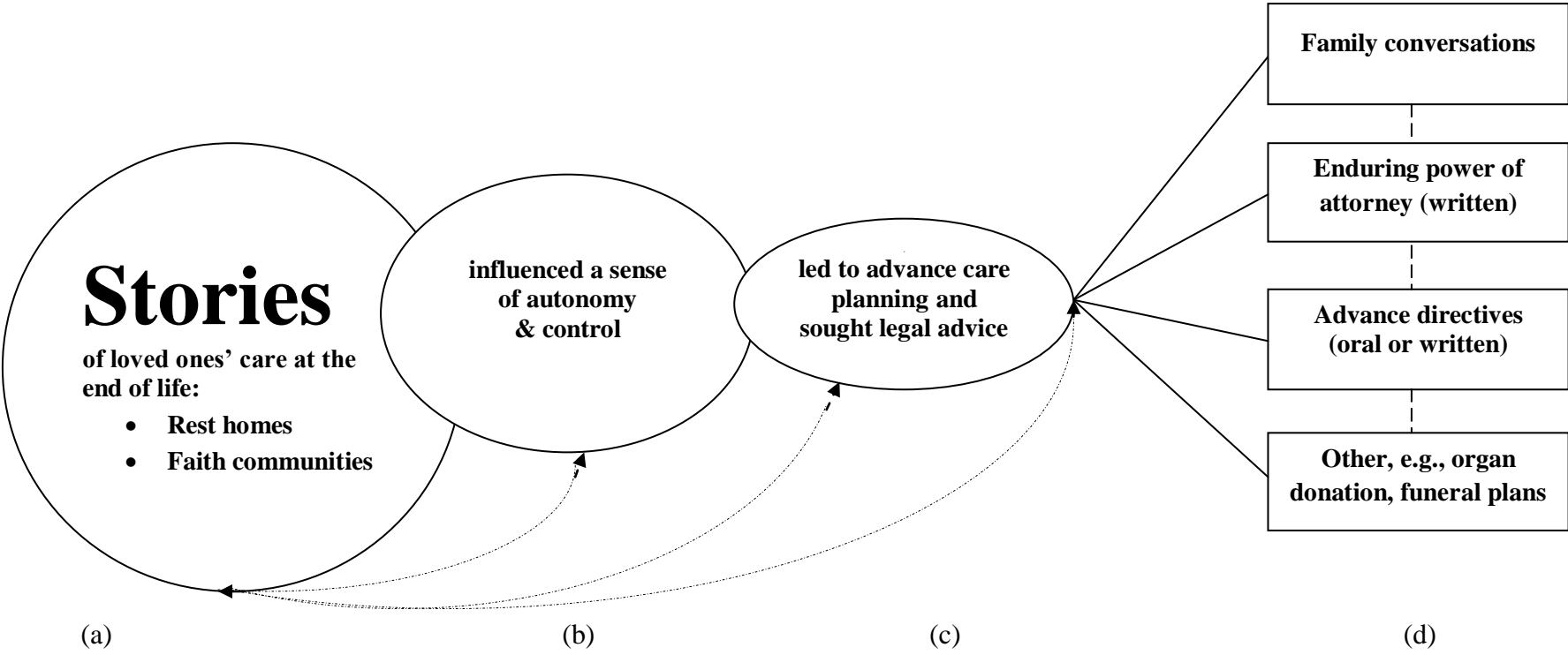
The topic of euthanasia was raised frequently during the group discussions. Nearly all of the respondents were against it except for one who expressed support for assisted dying in cases of intractable pain and the prospect of an undignified death. She also preferred to ‘end it all’ if she were stricken with Alzheimer’s disease. Another respondent

agreed with her position, however, she said she could not bring herself to “put the pillow” on her loved ones’ face. Moreover, there will be legal repercussions for those who assist in the procedure. Consistent with their church position, members of the Roman Catholic focus group considered euthanasia and abortion on the same level and accordingly, both were tantamount to murder. In one case, they argued that it meant killing the most vulnerable and older persons, and in the other, was killing the ‘unborn.’

One way of looking at the decision-making process of the eleven who completed their EPAs including the six who completed both EPAs and ADs can be described through the Chart 1 below. Completing an AD is a process of decision making. It is not linear (symbolised by the curved double arrows) and the document may be voided, changed or updated from time to time. This chart shows how storytelling about their loved ones care at the end of life can influence autonomy and decision-making. The respondents’ stories (a) enabled them to (re)connect with their loved ones which often raised a whole range of feelings including sadness, guilt, anger, to relief, connectedness, and gratitude for the support from faith communities. Upon reflection, respondents deduced that in the midst of advanced illness and death, they still have some personal autonomy and control (b) which led them to engage in advance care planning (c). The adult children may nudge their parents and grandparents to seek medical and legal advice. As a result, they initiated some actions (d) such as: family conversations about their values and end of life care preferences, EPA, AD and other future plans including organ/tissue/body donation as well as memorial and funeral plans.

Chart 1 AD: a process in decision making

Eleven respondents completed EPA only
Six respondents completed both EPA and AD



Peer feedback

As mentioned in the Methods Chapter, to help establish rigour and credibility of the project, I sought feedback from my peers. This included a one hour presentation of my project at the International Congress of Pastoral Care and Counselling held in Rotorua, New Zealand on 25 August 2011 (Tiano, 2012). The presentations were later published in a book (see Appendix F). Among the participants were counsellors, therapists, academics, chaplains, and clergy. Eleven attended the workshop: three Māori, three European-New Zealanders, four Australians, and one German.

Only one attendee from Australia signified that he had completed his AD and EPA. Three from Australia and two from New Zealand indicated some familiarity with the AD term. The rest of the five attendees were not familiar with the term at all.

The Māori chaplains declined the use of advance directives because of their well-defined roles during a health crisis. When someone died, the whānau/family and community knew what to do: the priest was in charge of the funeral service, someone in charge of cooking, others did the welcoming, child care, singing and cleaning. If the death took place in the hospital, they usually would need a whānau room to accommodate extended family who often came in large numbers. However, one Māori chaplain did convey his concern for his family if he were to develop a serious terminal condition. He implied that it would be particularly difficult for their oldest son who will be facing tremendous pressure and expectations. Thus, he could appreciate having family conversations about his values and wishes.

A German male academic said he was not familiar with the terms “advance directives” or “advance care planning”. He mentioned that he attended my presentation because at first he thought that the topic was about planning for retirement or something related. He was familiar with the term “informed consent” for a procedure such as, organ donation. Accordingly, if a patient was dying, the hospital would contact his or her next of kin to ascertain end of life care and decision-making. In the absence of a family or relative, the ethics committee was to be consulted for their recommendations. After the workshop, a German Social Work Professor clarified that they do have ADs but they call them “Patient’s Declaration”.

A participant from New Zealand did not know about the terms AD or ACP either. Being the youngest in the family, she was concerned that her role had been to defer to the oldest sibling. She now saw the need for their family to have conversations on advance

directives. Another shared about her mother's confusion with the different AD forms in various Australian states. Of particular interest was a chaplain's comment that ADs were not essential in the Australian aged care facility where he worked because the residents were spending their last days there. Resuscitation, surgeries and other aggressive treatment were not regularly provided. A participant from Queensland reported that due to a personal "health scare" twelve years ago, he decided to arrange his advance care planning including an AD, EPA and funeral plan. He added that planning ahead gave him a sense of freedom and peace and that his sons were most supportive of his wishes.

Conclusion

Four key findings were discussed, namely, communication issues, family support, faith perspectives and autonomy. Talking about death and dying was uncomfortable among many respondents yet rest homes proved to be a gateway to AD conversations. Those who completed ADs found them to be useful tools in communicating their future health care wishes. Respondents enjoyed strong local family support which had familial obligations towards caring for their sick and dying. Some were reluctant to fill out an AD because of the expectation that the family will take care of the decision making at the end of life. Among the prominent faith perspectives included a belief in death as a transition into an afterlife and responsibilities of the church as a faith community. Autonomy was the main value for the six who completed both EPAs and ADs. They cherished their independence, planned ahead, and preferred certain treatments if they become terminally ill. The peer feedback at the international conference provided a greater context from other cultures and disciplines. The Māori attendees conveyed about their ceremonies and traditions when someone was close to dying. Half of the attendees had heard about or were familiar with the term, advance directives but only one completed them. He was quick to share that due to a health crisis, he had worked on his an AD, EPA and funeral plan. Planning ahead provided him peace of mind and support from his family.

CHAPTER 6

Conclusion

Summary

The New Zealand Bill of Rights Act guarantees the right of consumers to refuse medical treatment. According to the New Zealand Code of Health and Disability, advance directives can be a written or oral instruction regarding future health care procedures such as life sustaining treatments. These directives will only be effective when one becomes mentally incapacitated. Advance directives are based on the value of autonomy in that adult consumers can make informed decisions about how they wish to be treated if they develop a life-limiting illness. Instead of merely considering it as another medico-legal form to fill out, it is vital to frame ADs in the context of advance care planning which the Ministry of Health describes as a process of shared future health care decision making based on their beliefs and values. The advantages of having ADs are several: they promote self-determination, and provide opportunities for consumers to express their wishes and treatment preferences before a health crisis occurs. Additionally, family members can benefit in knowing beforehand the patient's directives which can help reduce family stress during the time of grief. On the other hand, many challenges also abound, such as the validity of oral directives, mental capacity during the writing of ADs, relevance of prior instructions in today's rapidly changing technological world, access and storage issues, and applicability to cultures which value collective decision-making instead of individual autonomy. Still, critics and advocates agree that ADs can enhance communication in ascertaining patient values and health care goals.

The current research literature on ADs in New Zealand is minimal. This project's aim was to explore how older people among Dunedin's faith communities viewed ADs using narratives of respondents obtained through focus groups and interviews. Having acquired approval from the University of Otago Ethics Committee and the Ngāi Tahu Research Committee, twenty four participants were recruited to take part in the project. Their stories and responses were recorded, transcribed and analysed using different qualitative strategies such as prolonged engagement, member checks, triangulation, peer feedback, audit trail, thick description, reflexivity, content and narrative analyses.

All the respondents were of European descent ranging from sixty five to eighty nine years of age. Fourteen respondents were female, ten were male. Eleven completed EPAs and six completed both EPAs and ADs. On Question One, two spontaneous findings were examined, namely, the discomfort many respondents had in talking about death and dying, and rest homes as an effective gateway to such conversations. Their faith perspectives were the belief in God as the giver of life and as Divine Providence, an afterlife, and religious rituals. On Question Two, the benefits of ADs included improved communication, not being a burden, planning ahead, and considering treatment options. They also mentioned some disadvantages such as AD limitations, communication difficulties and problems with storage. On Question Three, the reasons for completing ADs were death of a spouse, concern for family/survivors, autonomy, and independent personality. The reasons for not completing an AD included fear of the unknown, avoidance, family expectations, faith in providers and lack of information.

Content analysis showed the different expressions respondents used to describe death and dying. The theme of death as a “gentle process” was used fifty six times in the sense that it was time to “let go”. The two top fears were dying in pain, hence, an “unpleasant process” and “losing cognition” such as being demented or in a vegetative state. The six who completed both ADs and EPAs valued autonomy and cherished their independence, engaged in family conversations, planned ahead, and expressed treatment preferences at the end of life.

Practice Implications

The practice implications highlight the need to improve communication in end of life care through storytelling, training of workers and community outreach.

Storytelling. As mentioned earlier, death and dying are oftentimes difficult conversation topics, thus, the discussion of ADs can be quite challenging. Nevertheless, the use of storytelling such as narratives about loved ones’ care in rest homes can provide a gateway to conversations on ADs and EPAs. Rest homes have both positive and negative connotations especially among older people either due to others’ experiences or their own anticipatory needs for long term care. Nonetheless, caution should be applied so that stories about rest homes do not end up merely with fatalistic overtones but as a means to engage in future health care options. Advance care planning which incorporates peoples’ beliefs and values can be broadened to include residential and end of life care,

thereby promoting empowerment through autonomy, control and shared decision making. Suffice it to say that planning for one's future health needs can begin much earlier before retirement. Taken in this context, ADs, EPAs and death and dying can become more relevant and less taboo.

Training of workers. To enhance effective communication in end of life care, professionals who practice in this field need training and become comfortable with their own sense of grief and mortality. As referred to in the Literature Review, an inverse correlation has been noted between death anxiety among social workers and their ability to disclose information about ADs (Marlys, 2009). Emphasizing the value of autonomy and self-determination, ADs can be presented as a way to encourage consumers to have some sense of control during the time of death. Social workers, especially those who work in gerontology and oncology would find it most helpful to familiarise themselves with the free downloadable materials at www.advancecareplanning.org.nz and complete their own directives. They could also avail of the National Advance Care Planning Cooperative's intensive training for health care professionals and social workers at different practitioner levels.

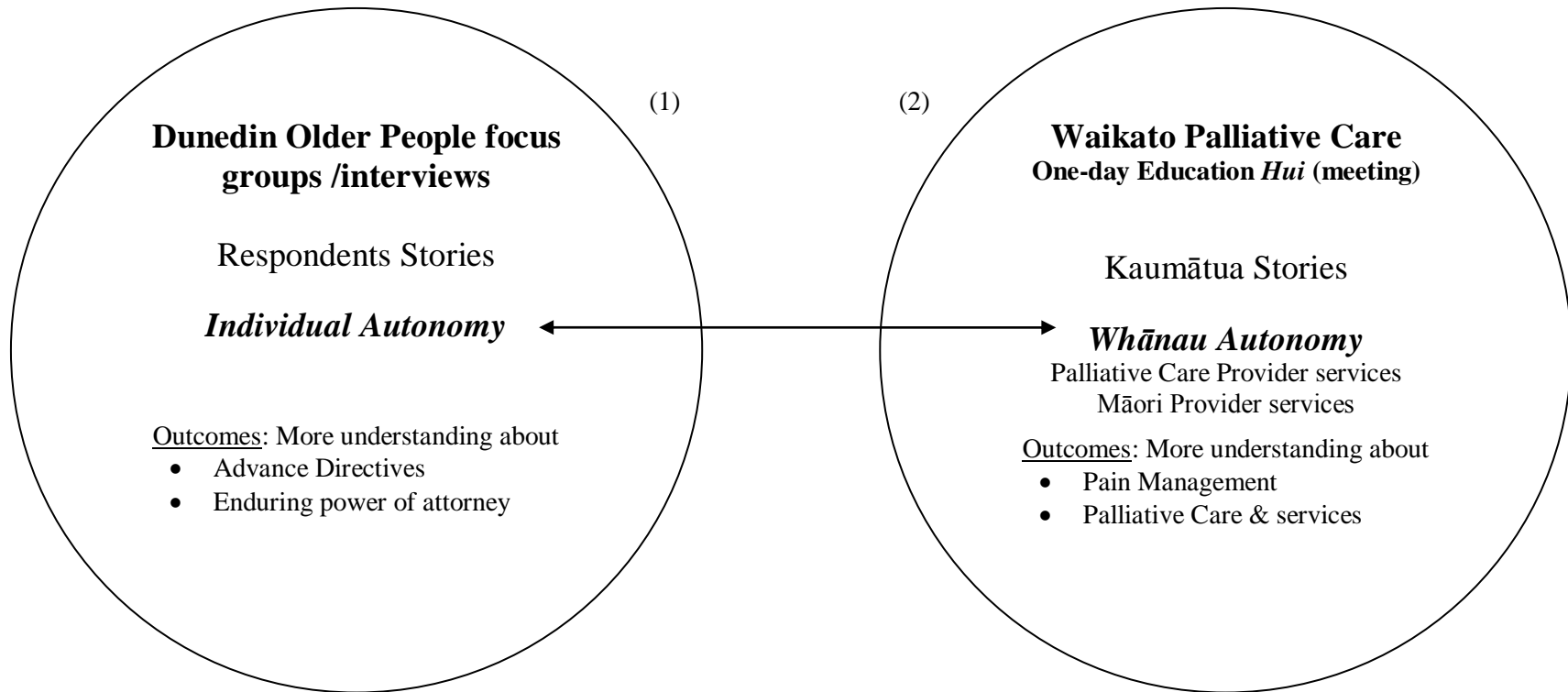
Community outreach. Results of this study underscore the need for community outreach and education in relation to ADs. Certainly, conversations on end of life care ought to take place before a health crisis. Perhaps, multi-disciplinary teams composed of health care staff, district nurses, social workers and chaplains can offer community outreach regarding AD information in places of worship, community centres, centres for ageing, and non-clinical venues.

A best practice approach has been ably demonstrated by Waikato Palliative Care and Māori Provider Services at a *hui* (meeting) regarding palliative care in celebration of the 2011 Hospice Awareness Week (Midland Cancer Network, 2011). During the morning session, the *kaumātua* (elders) shared their stories and asked questions about end of life care. This stage was essential to build trust and respect, thereby, helping to nurture *whānau* autonomy. Afternoon sessions focused on the clinical aspects which improved the attendees' understanding of pain management and palliative care. Hence, a combined use of cultural and clinical approaches proved to be an effective approach. Chart 2 below demonstrates how the respondents' stories (1) and the *kaumātua* (elders) stories (2) can provide a meaningful and culturally respectful practice in engaging Pākehā and Māori

regarding end of life care. Perhaps the *whānau autonomy* can be a model to reach out to Māori and Pacific Islanders, as well as other cultures who value collective decision making. Community outreach interventions have increased completion of ADs over multiple sessions (Gina, Dubois and Wagneur, 2008). More importantly, social workers can be particularly effective in improving patient understanding of advance directive forms (Luptak and Boulton, 1994).

On a final note, at the time of this writing, the End of Life Choice Bill on assisted dying is being vigorously debated in Parliament. But before it gets to a Parliamentary vote, would it not be more beneficial for consumers to engage first in a national conversation on advance care planning that addresses long term care, advance directives, enduring powers of attorney, palliative care and associated health care costs?

Chart 2 Community Outreach



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Appendix A

Research Approval

University of Otago Ethics Committee Approval



Academic Services
Manager, Academic Committees, Mr Gary Witte

11/132

10 June 2011

Professor A Barusch
Department of Sociology, Gender and Social Work

Dear Professor Barusch

I am again writing to you concerning your proposal entitled "**Advance Directives and Older People**", Ethics Committee reference number **11/132**.

Thank you for your letter addressing the Committee's concerns. We are grateful for your explanation of the overall implications and benefits of the research.

With regard to the possible bias in the results, we acknowledge that strategies will be used to reduce any bias, however our main concern was with the specificity of the pool from which participants are recruited. The Committee acknowledges and accepts that the data derived will be 'embedded in a qualitative paradigm', and we trust that this aspect will be reflected accordingly in the results. The Committee also accepts that the risks associated with the study are very low and is satisfied with your explanation.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

Approval is for up to three years. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

A handwritten signature in cursive that reads 'Gary Witte'.

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Professor H R Campbell Head Department of Sociology, Gender and Social Work

Appendix A

Research Approval

Ngāi Tahu Research Consultation Committee Approval



NGĀI TAHU RESEARCH CONSULTATION COMMITTEE

TE KOMITI RAKAHAU KI KĀI TAHU

31/05/2011 - 10
Tuesday, 31 May 2011

Professor Barusch
Sociology, Gender and Social Work
Dunedin

Tēnā koe Professor Barusch

Title: Advance Directives and Older People.

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 31 May 2011 to discuss your research proposition.

By way of introduction, this response from the Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum, it states "Ngāi Tahu acknowledges that the consultation process outlined in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology; they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the 2006 census.

The Committee notes the researchers have identified that, "Student researcher's sensitivity and competency in tikanga Māori", is of interest and ask how this is to be accomplished.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kāi Huirapa Rūnaka ki Puketeraki
Te Rūnanga o Moeraki



NGĀI TAHU RESEARCH CONSULTATION COMMITTEE

TE KOMITI RAKAHAU KI KĀI TAHU

We wish you every success in your research and the Committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 31 May 2011 to 01 December 2012.

The recommendations and suggestions above are provided on your proposal submitted through the consultation website process. These recommendations and suggestions do not necessarily relate to ethical issues with the research, including methodology. Other committees may also provide feedback in these areas.

Nāhaku noa, nā



PR MKCC

Mark Brunton
Kaiwhakahaere Rangahau Māori
Facilitator Research Māori
Research Division
Te Whare Wānanga o Otago
Ph: +64 3 479 8738
email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz

The Ngāi Tahu Research Consultation Committee has membership from:

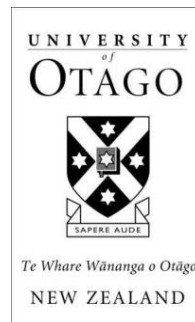
*Te Rūnanga o Ōtākou Incorporated
Kāi Huirapa Rūnaka ki Puketeraki
Te Rūnanga o Moeraki*

Appendix B

Information Sheet for Focus Group participants

Reference Number 11/123

July 2011



Advance Directives and Older People

INFORMATION SHEET FOR FOCUS GROUP PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the Aim of the Project?

This project seeks to explore older people's perspectives and reasons for completing advance directives (AD). An advance directive (AD) is a written or oral instruction that directs providers with regard to one's future health care choices particularly when facing a terminal illness. In accordance with the NZ Bill of Rights Act 1990, consumers may refuse or withdraw consent to services such as life sustaining treatments, or a do-not-resuscitate order. This project is being undertaken as part of the requirements for the Master in Social and Community Work degree.

What Type of Participants are being sought?

We are seeking participants who are members of English-speaking Dunedin churches and are 65 years old or older to take part in a focus group concerning advance directives. Due to the nature of advance directives, participants must be able to provide informed consents with regard to make health care decisions. No personal names or contact information will be obtained. The results will be made available to participants and may be published after the study to provide information and guidance to consumers and the Health and Disability Commissioner's Office.

What will Participants be Asked to Do?

Should you agree to take part in this project, you will be asked to:

Consent to take part in a focus group discussion on advance directives which may take up to 50 minutes. This session will be audio-taped for analysis.

We hope that these discussions will provide vital information to consumers regarding their future health care choices. All attempts will be made to keep the data, taped interviews and transcripts confidential.

Helpful resources such as information and support regarding advance directives will be made available. Please be aware that due to the sensitive nature of the topic, you may decide not to take part in the project without any disadvantage to yourself of any kind.

What Data or Information will be Collected and What Use will be Made of it?

This project involves an open-questioning technique to clarify the reasons for or against completing an advance directive. The precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. Consequently, although the University of Otago Human Ethics Committee is aware of the general areas to be explored in the interview, the Committee has not been able to review the precise questions to be used. You will be invited to volunteer for an interview. If you choose to do so, we will ask you to provide your name and contact information. This will be kept separate from other information you provide.

In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. Data obtained as a result of the research will be retained for **at least 5 years** in secure storage. Any personal information held on the participants [*such as audio tapes, transcripts, field notes, etc*] may be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

Participants will be given opportunity to view the data that relates to them and correct or withdraw the information. They will also be provided with the results of the study if they so desire.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity.

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

If you would like more information about advance directives please visit the New Zealand Medical Association website at www.nzma.org.nz or ask your local doctor. You may also enquire from Age Concern at 03 477 1040 or email: agecon@ageconcernotago.co.nz

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

[*Name of Student Researcher*] and/or [*Name of Supervisor*]

Noel Tiano

Amanda Barusch

Department of Sociology, Gender
Social Work

Department of Sociology, Gender and
Social Work

University Telephone Number: 03 479 5479
4795479

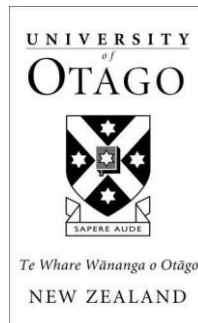
University Telephone Number: 03

Email Address: tiano098@student.otago.ac.nz Email Address:
Amanda.barusch@otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix B

Consent Forms



June 2011

Advance Directives and Older People

CONSENT FORM FOR FOCUS GROUP PARTICIPANTS

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. Personal identifying information [such as audio-tapes, etc] will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for at least five years;
4. Some open-questioning technique may be used to clarify the reasons for or against completing an advance directive. The precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. In the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I am reminded of my right to decline to answer any particular question(s) and also that I may withdraw from the project at any stage without any disadvantage of any kind.
5. I am aware that if any of the information covered in the project such as end of life care causes personal discomfort or risk, I will be referred to appropriate services for assistance.
6. I am aware that there is no remuneration, compensation, external funding or commercial use of the data.
7. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity should I choose to remain anonymous.

I agree to take part in this project.

.....
(Signature of participant)

.....
(Date)

I would like to volunteer for an interview. I can be contacted at:

Telephone number

.....
(Signature of participant)

.....
(Date)

Print Name

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix C

Focus Group Protocols

Focus Group Guide Questions



Focus Group questions

The line of questioning will largely follow an open-ended narrative format. The following general areas of inquiry will be sought.

1. Introduction to the purpose of the study (an advance directive (AD) is a written or oral instruction that directs providers with regard to one's future health care choices particularly when facing a terminal illness. In accordance with the NZ Bill of Rights Act 1990, consumers may refuse or withdraw consent to services such as life sustaining treatments, or a do-not-resuscitate order. This project seeks to explore older people's perspectives and reasons for completing advance directives.)
2. Would you share a story about a friend or a loved one's care at the end of life that has made an impression on you
 - What was the quality of the care he or she received? Adequate? Inadequate?
 - How might the end of life services have been improved?
3. What do you think about advance directives as a way to communicate your wishes?
 - Is there a need for advance care planning?
 - What are the benefits?
 - What are the harms or disadvantages?
 - Have you filled out an AD? Why or why not?
4. Does your faith or belief system influence your perspective on ADs? If yes, how?
5. Can you think of other ways to improve care and communication at the end of life?

Appendix C

Revised Focus Group Guide Questions

The line of questioning will largely follow an open-ended narrative format. The following general areas of inquiry will be sought.

Residency: Have you been a resident of Dunedin for 6 months or more?

Perspectives regarding advance care planning

1. Would you share a story about a friend or a loved one's care at a rest home that has made an impression on you? Perhaps that person has passed on or is still in the home
 - What was the quality of the care he or she received? (Adequate? Inadequate?)
 - How was pain control?
 - How might the services have been improved?

2. What do you think about an Enduring power of attorney? What about advance directives as a way to communicate ones wishes especially for those with serious conditions?
 - Is there a need for advance care planning?
 - What are the benefits?
 - What are the harms or disadvantages?
 - Have you filled out an AD? Why or why not?

3. How does your faith or belief system influence your perspective on advance directives?

4. Can you suggest of ways on how to improve communication and better care for the dying?

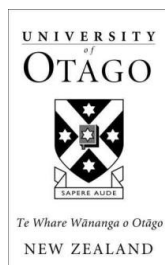
5. (Information about advance directive and purpose of study): An advance directive (AD) is a written or oral instruction that directs providers with regard to ones future health care choices particularly when facing a terminal illness. In accordance with the NZ Bill of Rights Act 1990, consumers may refuse or withdraw consent to services such as life sustaining treatments, or a do-not-resuscitate order. This project seeks to explore older people's perspectives and reasons for completing advance directives.

Appendix D

Participant Information Sheet

Reference Number 11/123

July 2011



Participant Information Sheet

1. What is your gender? (pls. tick one)
 - a. Male
 - b. Female

2. What ethnicity or racial group do you most identify with? (you may tick more than one)
 - a. European/New Zealander
 - b. Maori
 - c. Pacific Islander
 - d. Asian
 - e. African
 - f. Hispanic
 - g. Other: (please specify) _____

3. What age did you turn on your last birthday? _____

4. Do you have an enduring power of attorney? (pls. tick one)
 - a. yes
 - b. no
 - c. I don't know

5. Do you have an advance directive? (pls. tick one)
 - a. yes
 - b. no
 - c. I don't know

6. **OPTIONAL**
What is your income range? (please tick one)
 below \$10,000 per year
 \$11,000 to 20,000 per year

- ___ \$21,000 to 30,000 per year
- ___ \$31,000 to 40,000 per year
- ___ \$41,000 to 50,000 per year
- ___ \$51,000 and above
- ___ unknown

THANK YOU!!!

Appendix E

Chi Square Analysis between Genders

```

CROSSTABS
  /TABLES=EPOA AD BY Gender
  /FORMAT=AVALUE TABLES
  /STATISTICS=CHISQ
  /CELLS=COUNT COLUMN
  /COUNT ROUND CELL.
  
```

Crosstabs

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Enduring Power of Attorney * Gender	24	100.0%	0	.0%	24	100.0%
Advance Directives * Gender	24	100.0%	0	.0%	24	100.0%

Enduring Power of Attorney * Gender

Crosstab

			Gender		Total
			Male	Female	
Enduring Power of Attorney	Yes	Count	3	8	11
		% within Gender	30.0%	57.1%	45.8%
	No	Count	7	6	13
		% within Gender	70.0%	42.9%	54.2%
Total		Count	10	14	24
		% within Gender	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	1.731 ^a	1	.188	.240	.185
Continuity Correction ^b	.810	1	.368		
Likelihood Ratio	1.765	1	.184		
Fisher's Exact Test					
Linear-by-Linear Association	1.659	1	.198		
N of Valid Cases	24				

a. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 4.58.

b. Computed only for a 2x2 table

Advance Directives * Gender

Crosstab

			Gender		Total
			Male	Female	
Advance Directives	Yes	Count	2	4	6
		% within Gender	20.0%	28.6%	25.0%
	No	Count	8	10	18
		% within Gender	80.0%	71.4%	75.0%
Total		Count	10	14	24
		% within Gender	100.0%	100.0%	100.0%

Chi-Square Tests

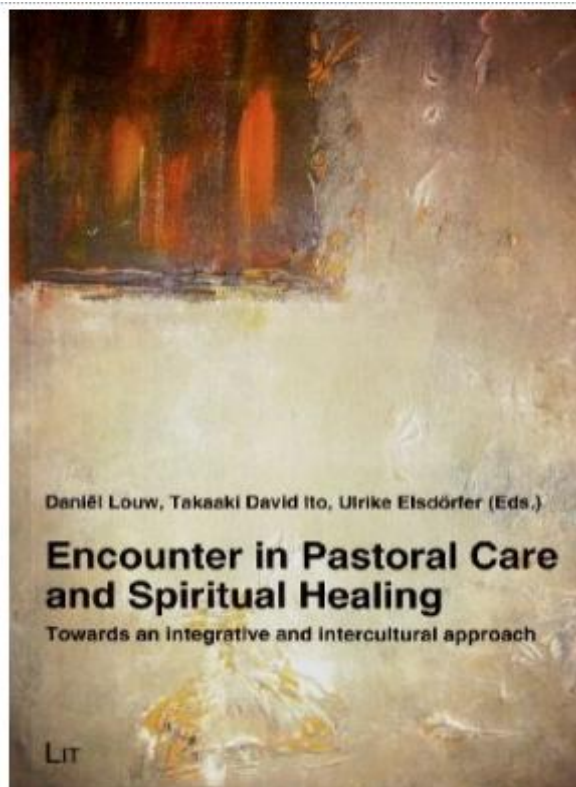
	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.229 ^a	1	.633	1.000	.506
Continuity Correction ^b	.000	1	1.000		
Likelihood Ratio	.232	1	.630		
Fisher's Exact Test					
Linear-by-Linear Association	.219	1	.640		
N of Valid Cases	24				

a. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 2.50.

b. Computed only for a 2x2 table

Appendix F

Published Article



Preface:	
Challenges to ICPCCC pastoral and spiritual policy: From the private consultation of the counselling room to the open and public space of market place encounters <i>Daniel Louw</i>	1
ICPCC–history and mission <i>Ulrike Elsdörfer</i>	5
Part I: Indigeneity: a challenge for Pastoral Care and Counselling	
Indigenous world views and therapeutic pathways <i>Mason Durie</i>	9
Refocussing and God Spaces: Holistic Counselling that allows for encounters with God <i>Diane Divett</i>	18
Advance directives and end of life care planning: A qualitative study among older adult church members in a New Zealand city <i>Noel Tiano</i>	35
Part II: An outstanding catastrophe: a challenge for Spiritual Care	
Narrative-Hermeneutical Care For the Survivors of the Great East Japan Earthquake and Tsunami, 2011 <i>Takaaki David Ito</i>	53