

FACILITATING PATIENT VOICE: A CASE STUDY ON ADVANCE DIRECTIVES
AND THE PRIMARY HEALTH NURSE

by

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Abstract

Advance directives are just one aspect of advance care planning. According to the New Zealand Nurses Organisation, advance directives are becoming increasingly common in New Zealand. Nurses are well positioned to take on an increasing role in advance directives, particularly in view of the expected burgeoning older population to which New Zealand is no exception. The literature suggests there is a role for primary health nurses in advance directives but no literature to date is available on this role in the New Zealand context.

The aim of this research was to determine primary health nurses' role in advance directives. A qualitative case study research approach was used to explore the knowledge, attitudes, experiences, and involvement of primary health nurses in advance directives. Semi-structured interviews were conducted with 13 senior primary health nurses from one New Zealand province. Two propositions informed the analysis: 1) primary health nurses currently do not have a role in advance directives; and 2) primary health nurses believe that advance directives can promote effective-end-of-life care. Watson's Theory of Human Caring was used as the theoretical framework to guide the study.

Three themes were identified from the analysis: encountering challenges, facilitating patient voice, and valuing the person. The findings revealed that primary health nurses had little or no significant experience or involvement in advance directives. Participants described knowledge inconsistencies about advance directives, in particular to related legalities. Nevertheless, participants had positive attitudes

towards advance directives and believed there was a role for primary health nurses in early advance directive conversations. They emphasised the importance of teamwork and envisaged their role as one of support to both the patient and doctor. Caring praxis underpinned the nurses' positive attitudes towards advance directives. These caring behaviours sustained the core values of patient autonomy and patient advocacy considered fundamental to sensitive advance directive conversations.

Many challenges were identified in terms of the nurse's role in advanced directives. These included cultural considerations for Māori in order to respect The Treaty of Waitangi principles and attending to the cultural needs of the individual Pacific Island groupings. Other challenges included unclear guidelines, unclear role delineation, ethical dilemmas and fragmented or complex communication issues across the primary/secondary health sector.

Results of this study may inform nurses of the need to establish nurse–patient relationships built upon trust and positive regard in order to support patients in advanced directive discussions. Implications for nurse educators include incorporating education directed at empowering nurses to participate in ethical decision making to enhance patients' end-of-life care. Given the importance of the multi-disciplinary responsibility in establishing advance directives, there is a need for further research regarding how health professionals could function together in the role of advance directive communication to best meet patients' needs.

Keywords: Advance Directives, Primary Health, Living Wills, Nurse, Primary Care (Health) Nurse, Advance Care Planning, End-Of-Life, New Zealand.

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Chapter 1: Introduction

Introduction

End-of-life care can be stressful for the whānau/family and health providers involved in the care of the dying person (New Zealand Nurses Organisation (NZNO), 2010). Decision making about end-of-life care is required when a person's condition deteriorates and death becomes the expected outcome. Most nurses are expected to be involved in caring for the dying patient at some stage of their career (New Zealand Nurses Organisation (NZNO), 2010). To improve patient-centred end-of-life care, nurses need to be familiar with the patient's and whānau (see Glossary p. 214)/family's wishes. Respecting patients' end-of-life choices plays an important role in improving this care. Nurses are well positioned to take on an increasing role in advance directives, particularly in view of the expected burgeoning older population (Ministry of Health, 2001a), to which New Zealand is no exception (NZNO).

The literature suggests that primary health is in an ideal position to initiate advance directives (Conroy, Fade, Fraser, & Schiff, 2009; Duffield & Poszamsky, 1996; Maxfield, Pohl, & Colling, 2003; Resnick & Andrews, 2002; Westley & Briggs, 2004). However, very little research is available on the role of the primary health nurse in advance directives. While many studies suggest there is a role for primary health nurses in advance directives (Auer, 2008; Conroy, et al.; Mogg, 2006; Newton, Clark, & Ahlquist, 2009; Towers, 1992), no studies specifically investigating this role were found. Therefore, a greater understanding into the primary health nurse's role in advance directives is required for further advancements to be made in this field. A qualitative study was undertaken using a

case study approach to reveal further understandings of advance directives and the primary health nurse.

Background

The proportion of New Zealand's population over 65 years of age is projected to almost double over the next 20 years (Ministry of Health, 2002). Change in primary care is on-going, with primary health now playing a more dominant role in delivering frontline services devolved from secondary care (Cross, 2010). With an ageing population, more patients are now choosing to die at home (Ministry of Health, 2001a). Therefore, it is possible primary health will have increased responsibilities in developing advance directives to provide effective patient-centred end-of-life care. Given their important role in providing continuity of care to such patients (Ministry of Health, 2001a), primary health nurses are well positioned to participate in this work.

Primary health has a large interface with the public. Large numbers of patients are usually seen at least annually allowing the development of trusting and therapeutic relationships between the professional and patient. These relationships place the primary health nurse in a pivotal position to support the needs of the patient in advance directives.

Advance directives are related to a patient's right to self-determination, the right to refuse treatment, and the right to choose. These factors align closely with the current New Zealand Nursing Council's nursing competencies (Nursing Council New Zealand Te Kaunihera Tapuhi o Aotearoa, 2007). The first position statement by the New Zealand Nurses Organisation about advance directives was released in 2010. This

statement supported the use of advance directives and advance care planning in end-of-life care (NZNO, 2010).

Advance care planning has been gaining momentum in New Zealand with strategic planning currently underway to develop national advance care planning guidelines. At the Inaugural International Advance care Planning Conference (2010) held in Australia, several papers were presented by New Zealand health professionals. These conference papers included: “Taking advance care planning to our community” (Stewart & Naish, 2010, April), a “Primary care palliative care project” (Rishworth, Bastion, & McLeod, 2010, April), “Government department and NGO (non-governmental organisation) working together to support advance care planning in the community” (Read, 2010, April), and “Conception to gestation: preferred priorities for care (PPC) advance care planning pilot” (Daltrey & Clark, 2010, April). Although nurses were not the focus of these presentations, they indicated where New Zealand sits internationally in respect to advance care planning. New Zealand practice is in its infancy in regard to this.

My Position

As a Registered Comprehensive Nurse (RCN) I have worked as a primary health nurse in general practice in New Zealand for the past ten years. I have witnessed an increase in palliative care in the primary health sector, with the New Zealand primary health team having a significant involvement with those nearing end-of-life (Ministry of Health, 2001a). Through past palliative care studies and my experience in working with palliative care patients I have recognised the importance of effective advance care planning (see Glossary p. 211) in promoting holistic (see

Glossary p. 212) care and empowerment of the patient and whānau/family to support their end-of-life choices.

A number of experiences related by colleagues and those witnessed by myself contributed to my interest in advance directives. In particular, the experiences of two patients illustrate how advance directives helped them achieve a peaceful death. The first, an elderly patient, managed to achieve her wishes – to die at home surrounded by her family. She had been admitted to hospital a number of times in her later stages of ill health, had become bedridden and was adamant she did not want to go into hospital or care again. After suffering an acute health event at home she was offered palliative care, and died peacefully at home. The family have often recounted the great sense of relief they felt in knowing their mother died peacefully with her end-of-life choices respected.

The second patient was terminally ill with cancer and had a change of mind about her care late in her illness. She initially was adamant she would remain at home for the duration of her illness. As her condition worsened her desire to remain at home changed. This led to further discussions among the patient, her family, me, the general practitioner and hospice staff, about other options for her end-of-life care resulting in several visits to the local hospice; her final days were spent in hospice care. Much of the stress on her and her family was alleviated as she made her end-of-life wishes known to those involved in her care. The health team was then in a position to accommodate her wishes.

Both patients had verbal advance directives about their preferred place to die, which were supported by the primary health team. Both had long-term relationships with (and trust in) their general practitioner and primary healthcare nurses. This, coupled with the primary health team's knowledge of the patients' values and preferences about their end-of-life, provided the backdrop for successful implementation of their directives in a caring and dignified manner.

I believe, as nurses, we are bound to provide a caring and dignified climate that supports the patient, ensuring they feel cared for, supported and valued as the total person – physically, mentally, psychologically, socially and spiritually. My personal philosophy of nursing is driven by two focuses, that of holistic care and by my belief that all people be valued and acknowledged as having a role in contributing to our society. Communication, caring and relationships are the essence of my nursing practice and are aligned with Watson's Theory of Human Caring. I have witnessed and been a part of the implementation of advance care planning and pre-emptive care for those nearing end-of-life. My philosophy, my beliefs, what I have witnessed and my exposure to the developments in the field have provided the impetus to want to investigate this further. These aspects led me to focus on just one facet of advance care planning, that of advance directives. As advance directives are designed to provide effective end-of-life care, I elected to determine the primary health nurse's knowledge, attitude, involvement and experience in advance directives with a view of improving our overall care and best practice.

Significance of the Research

With the proportion of New Zealand's population over 65 years of age expected to double over the next 20 years (Ministry of Health, 2002), large numbers of people will require more healthcare and palliative care resources. With more healthcare services devolved to primary care, increased numbers of patients seeking these services will add to the demand on general practitioners and primary health nurses, integral to the continuity-of-care for the dying patient and their whānau/family (Ministry of Health, 2001a). With the focus on patient autonomy in end-of-life care and growing concerns about our burgeoning population, it is timely to be examining the primary health nurse's role in advance directives. This research will provide a platform for other research in advance directives in New Zealand, and will generate new knowledge about the primary health nurse's role in advance directives.

Definition of Major Terms

Advance directives.

An advance directive is defined by the New Zealand Health and Disability Commissioner Code of Health and Disability Services Consumers Rights Regulations (1996), as "*a written or oral directive:*"

a) "By which a consumer makes a choice about a possible future healthcare procedure"

b) "That is intended to be effective only when he or she is not competent"

(Health & Disability Commissioner, 1996).

Advance directives recognise a person's right to self-determination and provide information for families, health providers, friends and caregivers about end-of-life

preferences should the person become unable to make healthcare decisions (Johnstone, 2009; New Zealand Medical Association, 2004; Wareham, McCallin, & Diesfeld, 2005). They give nurses and other healthcare professionals an understanding of patients' values and wishes. More importantly, however, advance directives are vehicles for in-depth, on-going discussions between healthcare professionals, patients and families (Pautex, Herrmann, & Zulian, 2008) required to make informed choices.

Advance directives may be oral or written. A written advance directive may be referred to as a living will, and is a legal document (Crane, Wittink, & Doukas, 2005). The competent patient may legally appoint an enduring power of attorney (see Glossary p.212) to execute their healthcare directives in the event the patient becomes incapacitated (Crane, et al.). There are a variety ways of interpreting advance directives; from a traditional "do not resuscitate" policy at end-of-life care to incorporating a newer much broader holistic approach to end-of-life care. For the purpose of this study the more holistic approach is considered. Traditional advance directives, such as statutory wills and surrogate appointments created by legislative provisions setting specific requirements, focused on a limited set of circumstances, such as when a person is in a persistent vegetative state or death is imminent regardless of treatment options (Hickman, Hammes, Moss, & Tolle, 2005). However the newer more holistic advance directives are not limited to content or legislative rulings but a plan developed through a number of interactions that are specific to the patient's values, relationships, culture and medical condition. This process engages shared decision making between the patient and those closest to them (Hickman, et al.).

Primary health

The New Zealand definition of primary healthcare has been drawn from the international conference of primary healthcare, held in Alma-Ata, 1978. It is considered to be essential healthcare and is the first level of contact individuals, family and community have with the national health system. Primary healthcare providers are ideally situated as close as possible to patients' places of work or residence. It aims to be affordable, develop self-reliance and determination, and is the first part of a continuing healthcare process (World Health Organisation, 2001). The nurses in this study each work at the first level of care in primary health and are part of a primary health team.

Purpose of Research

The purpose of this qualitative case study was to uncover primary health nurses' knowledge, experience and attitudes about the primary health nurse's role in advance directives.

The Research Question

What role do primary health nurses have in advance directives?

The Propositions

Two propositions were identified through the literature and my practice experience; these propositions informed my analysis: 1) Primary health nurses currently do not have a role in advance directives; and 2) Primary health nurses believe that advance directives can promote effective-end-of-life care.

The Objectives

- Explore and describe primary health nurses' general knowledge and attitudes relating to advance directives
- Describe the primary health nurse's experiences with advance directives
- Describe the primary health nurse's role with advance directives in primary health

Theoretical Framework

Watson's Theory of Human Caring was used as the theoretical framework to help guide this study. The concept of care is the foundation to all nursing activities (McGee, 2005) – caring and caring behaviours are central to effective provision of nursing care. Caring behaviours provide an improved focus in the provision of healthcare, and facilitate for the patient a sense of security and improved satisfaction with their care (Moore, 2002). These characteristics are fundamental to the nurses' role in advance directives. Watson's Theory of Human Caring focuses on the integration of mind/body/spirit while taking into account caring, healing and curing (Watson, 2000). This results in therapeutic nurse-patient relationships believed to be the "core" of nursing (Watson, 2006). Watson's theory is based on 10 carative factors (see Appendix A), which evolved into the "caritas processes" (see Appendix B). Intertwined with these processes are the transpersonal caring relationship and the caring occasion (Jesse, 2010). Watson's theory, although originally developed with a focus on nurse-individual interactions, is congruent with approaches to community health and health promotion; all of which fall into the scope of the primary health nurse (Rafael, 2000).

Ethical Considerations

Following consultation with Māori and Pacific health managers, hospice and hospital personnel, ethics approval was sought and granted on 3 July, 2010 [CEN/10/EXP/29 3 July 2010] (see Appendix C). Ethical principles according to the Operational Standard for Ethics Committees (Ministry of Health, 2006) guided my process to ensure all ethical responsibilities were met.

Research Approach

A qualitative case study design was utilised for this study. Ten individual primary health providers in one New Zealand province served as the setting for my research. Thirteen senior primary health nurses agreed to participate. I conducted one semi-structured interview with each participant and analysed the data using Braun and Clarke's (2006) six phase framework. Three key themes emerged from the findings – encountering challenges, facilitating patient voice and valuing the person.

Cultural Considerations

In this study I used The Treaty of Waitangi guidelines of partnership, participation and protection to show respect to ethical issues important to Māori. The study met the primary ethical principles of the “Te Ara Tika” draft in relation to Māori research (Hudson, Milne, Reynolds, Russell, & Smith, 2010). A Māori health co-ordinator from the local primary health organisation agreed to assist in my study to ensure cultural appropriateness and safety, and assist in analysis.

Structure of Thesis

A literature review is presented in Chapter Two, focusing on the role of the nurse in advance directives and advance directives in the primary health environment. Included are an historical overview, legislative considerations, and patients' perspectives of advance directives.

Chapter Three outlines the theoretical framework used for this study. Watson's Theory of Human Caring was used to guide this study.

Chapter Four provides a description of the research approach used in this study. The exploratory case study approach is described in detail as well as the ethical and cultural considerations.

Chapters five, six and seven present the three key themes representing the findings of this study. The three themes identified are: encountering challenges, facilitating patient voice and valuing the person.

Chapter Eight, the discussion chapter, outlines the conclusion of the study and describes the implications for nursing practice, nursing education, and future nursing research.

Summary

This chapter outlined the background to this study and introduced the rationale for investigating the primary health nurse's role in advance directives. Advance directives are becoming increasingly common in end-of-life care (New Zealand

Nurses Organisation (NZNO), 2010). The primary health team is considered pivotal to end-of-life care. Therefore, primary health nurses need to be aware of their roles and responsibilities in this work. While the literature suggests there is a role for the primary health nurse in advance directives, no literature was found that investigates this role from a primary health nursing perspective. Chapter Two reviews the literature relevant to this topic.

Chapter 2: Literature Review

Introduction

This chapter reviews reported research on advance directives and their relationship to primary health, in particular to the primary health nurse. The purpose of this review was to establish current knowledge about nurses' roles in advance directives and determine gaps in the literature.

A search of electronic databases *Cinahl Plus* with full text, *Medline* with full text and *ProQuest* was carried out using the following keywords: advance directives, primary health, living wills, nurse, primary care nurse, advance care planning, end-of-life, and New Zealand. The search was limited to English language, and included full text, peer reviewed journal articles written between years 2003 and 2010, chosen to provide seminal and current views as well as opinions. However, supplementary strategies were used to identify further material; a manual search of relevant textbooks of which two were used, a manual search of six relevant journals, conference proceedings and a review of the reference lists of the peer reviewed articles. Articles selected for review focused on understanding advance directives and their implications for nursing and primary healthcare and are mostly from the USA and the UK. This literature review includes findings from quantitative studies, qualitative studies, reports, guidelines, and commentaries, other literature reviews, essays and grey literature. The grey literature outlines the New Zealand Medical Association's approach to advance directives and the New Zealand Nurses Organisation position statement to place advance directives in the New Zealand context.

A gap in the literature was found that specifically investigated the primary health nurse's role in advance directives. Studies of home health nurses, hospice, elder-care and oncology nurses' roles in advance directives were critiqued. Although they do not fit the frame of reference to primary health in this study, these settings and services are often conducted in the community or as outpatient care, therefore have similarities and relevancy for this study. In this literature review chapter, the living will versus advance directives will initially be presented, followed by an historical overview, legislative considerations and the patient's perspectives on advance directives. This sets the background and the context for the remaining section of the review. This includes the role of the nurse in advance directives, the primary health nurse and advance directives, and finally, advance directives in primary health.

Advance Directives versus Living Wills

Advance directives are part of advance care planning in developing end-of-life choices with a patient in accordance to their wishes for future medical care (Pugno, 2004). An advance directive, as defined by the New Zealand Health and Disability Commissioner Code of Health and Disability Services Consumers Rights Regulations (1996), is a written or oral directive a) by which a consumer makes a choice about a possible future healthcare procedure; and b) that is intended to be effective only when he or she is not competent. An advance directive in New Zealand does not have to be a formal written document, nor does it have to apply when someone is terminally ill or necessarily relate to life saving measures (Paterson, 2007). A living will is a written form of an advance directive (Crane, et al., 2005). The first living will was introduced in 1969 in the USA and is considered a tool to allow an individual to express healthcare

choices when a person is no longer able to do so. They typically focus on potentially life prolonging treatments when a person is “facing imminent death regardless of treatment” or in a “constant vegetative state” (Hickman, et al., 2005, p. S27). It is more common in New Zealand to speak of an advance directive as opposed to a living will as it covers a wider range of health situations (Paterson). Pugno also suggested advance directives may be more valuable in that they are more focused on patient values and desired outcomes as opposed to the mechanisms of how to achieve these outcomes.

Advance Directives Historical Overview

Prior to 1970, healthcare ethics stemmed from paternalism, where the physician made all patient care decisions. These decisions were focused on preserving life, thus disallowing personal control over the dying process. Literature shows this approach has shifted to patient oriented self-determination (Brown, 2003). However, as far back as 1914, a judge from the USA – Justice Cardozo – introduced the right of self-determination to uphold consent for invasive medical procedures. The development of mechanical ventilators and cardiopulmonary resuscitation between 1930 and 1950 created suspicion of defying nature. This eventually led to an increased interest in death and dying, patients’ rights, hospice care, and in the 1960s, the concept of advance directives and living wills (Brown).

Following two pivotal cases that occurred in the USA involving ethical and legal dilemmas, along with growing public assumption that unnecessary care was being given to dying patients, the advance directives concept developed further. The development of technology at such a rate as to be unmanageable, as well as rising costs and consumerism, has added to the advance directive concept. These factors

were instrumental in the development of the Patient Self-Determination Act (PSDA) of 1990 in the USA (Brown). This act legislated that all hospitalised patients be given written information on their rights with regards to advance directives and decision making (Brown; Matesanz Mateu, 2006).

Respecting Patient Choices is an advance care programme in La Crosse, Wisconsin, USA (Mogg, 2006). This programme encourages people to reflect on and articulate their values, beliefs, goals and preferences for end-of-life care in the event they become unable to communicate. Consultants are trained to teach nurses, social workers and allied health professionals' skills to hold end-of-life discussions (Mogg). This programme forms the basis of advance care planning throughout much of the USA and was piloted in Melbourne, Australia 2002 (Austin Health, 2006). It is currently being rolled out across South Australia to all acute sites, including community health practices, aged-care sites and primary care practice nurses (Government of South Australia, 2010).

Similarly, advance care planning is part of the end-of-life strategy in the UK promoting voluntary discussions between patients and their health providers. The Preferred Priorities for Care (PPC) programme (NHS National End Of Life Care Programme, 2007), initially rolled out as Preferred Place of Care in 2005 (Royal College of Nursing, 2010) is currently used nationwide. Patients are encouraged to voice any concerns, important values or preferences for care or treatment that may be necessary in the future. An advance statement (advance directive) may or may not be made as part of the process. PPC advance statements may be made by anyone at any time with or without a life threatening illness (NHS National End Of Life Care

Programme). The Gold Standards Framework (GSF) developed in 2001 by Dr K. Thomas to improve palliative care in primary health in the UK also includes advance care planning in order to address patient symptoms, problems and concerns. A review of the GSF conducted in 2010 shows further research is necessary to determine the extent GSF enhances alignment with advance care planning (Shaw, Clifford, Thomas, & Meehan, 2010).

National literature

Around the same time of the introduction of PSDA in 1990, the New Zealand Bill of Rights Act was passed, providing consumers the right to refuse treatment, under Section 11. This was underpinned by the philosophy of consumer autonomy, and led to the development of the New Zealand Code of Health and Disability 1996 (Wareham, et al., 2005), which gave patients the right to use an advance directive (Health and Disability Commissioner, 1996).

Advance directives are recognised by the New Zealand Medical Association (NZMA) (2004) as a concept that respects the competent patient's right to make healthcare decisions. Initial policies were developed in 1995 and the current policy highlights potential risks, particularly in regards to views changing over time. This accentuates the importance of fully informing patients about all available options. The NZMA also emphasises that advance directives are not just the signing of a form but more importantly a process of communication associated with understanding and decision making (NZMA). This concept is supported in a plethora of literature (Pautex, et al., 2008; Thompson, Barbour, & Schwartz, 2003). There are, however, risks and benefits associated with the use of advance directives. Risks identified by

Johnstone (2009) include the possibility of patients making unreasonable choices, the potential lack of safeguards should they make unreasonable choices and the complexities involved with patients changing their minds as their health status alters. Benefits include the promotion of autonomous decisions, protection from futile treatment, strengthening communication with loved ones and enabling the person to plan for death.

The New Zealand Ministry of Health has developed two advance care planning documents with the purpose of implementation after final reviews. The first document, “*Advance care Planning for Adults: An overview*” is adapted (with permission) from the UK publication *Advance Care Planning: A guide for health and social care staff* and was developed to provide standardised information about advance care planning and legislation in New Zealand (Ministry of Health and Hospice New Zealand, 2010). The second document, “*Advance Care Planning for Adults: Planning for your future care*” is designed to inform the public about advance care planning and what the available options are. It includes information on advance care planning, advance directives and enduring power of attorneys’. This document is adapted from the NHS National End-of-life Care Programme (Ministry of Health, 2010a). According to these documents, advance care planning may include an advance directive, which is able to be changed at any time while the patient remains competent (Ministry of Health, 2010a; Ministry of Health and Hospice New Zealand, 2010). The New Zealand Royal College of General Practitioners has responded in support of these consultative documents and has added the importance of the benefits to family members, such as less anxiety and stress after a loved one has passed away. They also suggest it may be more useful to focus

on goals rather than treatment for particular circumstances and reiterate the importance of the interface between primary and secondary care to ensure information is accessible when required (The Royal New Zealand College of General Practitioners, 2010). Around the same time the National Advance Care Planning Co-operative was established, to drive and design advance care planning services in New Zealand. The two advance care planning documents are currently being amended to reflect the feedback of the Co-operative (Ministry of Health, 2010b) . These documents have been designed to increase the introduction and effectiveness of advance care planning in New Zealand in an effort to provide quality patient centred care.

The New Zealand Nurses' Organisation (NZNO) has also implemented its first policy on advance care planning in 2010, which is discussed later in this chapter under "The role of the nurse in New Zealand".

Ethical and Legislative Considerations

Advance directives are founded on the principle of validity and applicability, and may have legal implications (Griffith, 2004). However, the legally binding nature of advance directives can be controversial (Griffith; Matesanz Mateu, 2006; Sahm, Will, & Hommel, 2004) and must not put health professionals in contravention of their professional code (Griffith; Matesanz Mateu). Should conflict arise over advance directives the matter is taken to court for settlement (Griffith).

Consent for advance directives must be volunteered by a legally competent person who is fully informed about the decision's being made. This competence is

assumed unless a qualified practitioner deems otherwise (LaPorte Matzo & Witt Sherman, 2006; Matesanz Mateu, 2006). The consent may be written, oral, by co-operation or can be refused by the patient. Healthcare professionals are unable to influence patients but may act as a source of information, advice and counsel (Matesanz Mateu).

Patient's rights are identified in The New Zealand Code of Health and Disability Services Consumers' Rights which came into force in 1996. These rights are based on the principle of informed consent (Docherty, 1996). The code gives the right to use advance directives, unless excluded under other provisions of the act (Health and Disability Commissioner Regulations, 1996). Advance directives are described in the code as written or oral directives based on a consumer's choices about possible future healthcare, intended to come into effect should he or she become incapacitated. Several clauses in the code provide guidance for health providers stipulating the provider is not obliged to act in breach of duty; however, they are obliged to take reasonable care to honour the code, take reasonable action in the circumstances and comply with their duty of care. There are also legislative provisions to override advance directives under certain circumstances (Health and Disability Commissioner Regulations, 1996). Ambiguous language, proxies or families disagreeing about the interpretation of the patient's wishes may become problematic if the need arises to activate an advance directive. Johnstone (2009) cautions patients' advance directives may be difficult to validate and can inadvertently lead to disastrous non-treatment options being made, should urgent decision making be required. Although deemed absolute, advance directives may be difficult to enforce, with little or no legal recourse in cases where they are not

honoured (Johnstone).

At present, the NZMA respects the competent patient's right to make healthcare decisions in advance directives. They recommend patients explore all facets of advance directives, including the patient's appointment of an enduring power of attorney to make healthcare decisions should they become incapacitated (NZMA, 2004). Johnstone (2009) argues advance directives are under-utilised in clinical situations despite the expectation that they guide end-of-life care. This has resulted in the emphasis of advance care planning moving away from signed documentation and towards improving processes in communication and preparing families for the future (Johnstone).

The ethical and legal complexities described in this section highlight the importance of health professionals' awareness of their boundaries and roles in advance directives. Ethical and legal boundaries protect the patient and the healthcare provider, and are crucial to the implementation of advance directives.

Patients' Perspectives on Advance Directives

Past research has shown treatment decisions are often made by physicians with inadequate acknowledgement of the patient's perspectives and wishes (Pautex, et al., 2008). Douglas and Brown (2002) argue, from the results of their study of 30 patients, most people believe they have choices for end-of-life care and advance directives ensure they get the treatment they desire.

Brown (2003) concurs patients are more likely to formulate advance directives

in an environment where patient autonomy thrives and where health professionals are comfortable with the idea of advance directives. Nursing home (Pekmezaris et al., 2004; Solloway, LaFrance, Vakitas, & Gerken, 2005) and hospice patients (Teno, Grunier, Schwartz, Nanda, & Wetle, 2007) are more likely to report having advance directives than those in hospitals, suggesting health professionals may be more comfortable with advance directives in these settings.

Munday, Dale and Murray (2007) suggest patient preferences assist in advance care planning but are not always complied with. Complex disease trajectory and limited resources may impede their delivery. However, in their study of advance directives at three palliative care units in Europe, Pautex et al. (2008) discovered that advance directives indicating patient preferences were achievable in palliative care units. Their study conducted with 53 patients in the palliative care units resulted in 25% of the patients choosing to complete an advance directive of which all directives were met. There was no significant difference in the socio-demographics of those who completed advance directives and those who did not (Pautex et al.). Other research, however, suggests there is strong evidence that those who complete advance directives are more likely to be white, female, over 65, Christian (McCarthy et al., 2008; Resnick & Andrews, 2002; Tilden, Tolle, Drach, & Perrin, 2004), unmarried (Pautex, et al., 2008) and educated (Pautex, et al., 2008; Wissow et al., 2004). Ramsaroop, Reid and Adelman (2007) argue however that some studies reveal there is no difference in educational background of those who take up advance directives.

An American study of 220 elderly community residents contends that patients

living in a non-private residence, who have someone to listen to them and no evidence of depression, are more likely to complete advance directives (McCarthy, et al., 2008). These residents also indicated a preference for comfort over life-extending care, supporting Resnick and Andrews (2002) similar findings from their earlier study of 135 older adults.

Patient choices are characterised by uncertainty (Munday, et al., 2007). There are a number of reasons patients may choose to formulate advance directives, such as declining health, not wanting to lose control or become a burden to others. On the other hand reasons patients may choose not to complete advance directives may include family disagreement, irrelevance to time of life, or lack of access to information. Further reasons patients choose to or choose not take up advance directives are provided in the appendices (see Appendices D and E).

Sahm et al. (2005) studied the attitudes of cancer patients, healthy controls, nursing staff and doctors towards advance directives and found that a quarter to a third believed they may be abused or used in inappropriate medical situations. Of concern was their finding that half of the 400 participants' feared patients could be pressured into writing advance directives.

Other research revealed patients lacked an understanding into advance directives, even among those who had completed them (Jezewski & Meeker, 2005). This American study of 76 chronically ill persons showed the concept of healthcare proxies was a little easier to understand than the concept of advance directives. The study highlights the importance for health professionals to have a thorough

understanding of patient's perspectives about advance directives and be familiar with the associated complexities. (Jezewski & Meeker).

An outreach programme to educate the community on advance directives was developed in 2007 in the USA by two critical care nurses (Later & King, 2007). The programme was designed to allow people to talk about and receive information about advance directives. The programme was so successful that it was repeated the following year. The authors' experience as critical care nurses led them to believe that introducing advance directives to hospitalised patients compounds the stress and impact of the illness or accident that has brought them to hospital. Furthermore Later and King believe the patients and their families are often not prepared to make these decisions with health providers who know very little about the patient. They suggest interactive sessions between the patient and health professional are the most effective way to introduce advance directives. As the nurse is often responsible for communicating end-of-life information to the patient, Later and King suggested nurses are in a prime position to provide education to the community (Later & King).

Completed advance directives are linked to increased satisfaction with end-of-life care (Detering, Hancock, Reade, & Silvester, 2010; Griffie, Nelson-Marten, & Muchka, 2004; McCarthy, et al., 2008; Pautex, et al., 2008; Schwartz et al., 2003) and may lead to treatment decisions consistent with the patient's values (Schwartz, et al). A number of studies suggest discussions with families around advance directives strengthen health professional and family relationships, promote more honest conversations and help patients to not feel so alone (Detering, et al.; Pautex, et al.; Ramachandran, 2008; Teno, et al., 2007). Furthermore, interim discussions with the

doctor and regularly reviewed decisions have been seen to improve the stability of the directives (Crane, et al., 2005).

Research conducted in the USA examining attitudes, experiences and preferences of 20–80 year old patients in advance directives, from a managed care organisation, revealed 62% of participants felt it was up to them to raise the subject. Findings also revealed that 70% of participants would feel comfortable if their managed care provider (primary) initiated the conversation. Subjects in this study included those who had been enrolled as patients for a minimum of three years in the organisation and were over 20 years of age. Those over 60 years of age appeared to feel more comfortable with these discussions (Jackson, Rolnick, Asche, & Heinrich, 2009). Likewise a randomised–control study conducted in Melbourne, involving 309 over 80 year old patients, revealed that appropriate introduction of advance care planning by nurses and allied staff enabled patients' wishes to be determined, documented and respected at end-of-life (Detering, et al., 2010). Patients welcomed the initiation of discussions where there was more focus on goals for care. These discussions proved to be more successful when family was involved or a surrogate appointed (Detering, et al.).

Emanuel and Scandrett (2010) recommend routinely including advance care discussions and documentation in care practices, determining people's evolving values to ensure quality care is received at end-of-life. They contend most Western cultures have a tendency to deny death and see this as part of the challenge in achieving quality dying (Emanuel & Scandrett).

As suggested by Solloway et al. (2005), there are many significant differences in the foundation and existence of advance directives. Declining health, environmental factors, socio-demographics, patient interpretation and interaction with social systems are key factors that underpin patient perspectives and decision making in advance directives.

There is a paucity of research in New Zealand on the patient and advance directives. Wareham et al. (2005) maintained that consumers do not have equitable access to informed decision making. Left unchallenged this may create psychological, spiritual, cultural or moral harm to patients. Information is acquired through the media and the internet, giving the consumer more knowledge, thus preparing them to ask questions. This places the nurse in an ideal position to support patients to ask questions and provide information that may affect their healthcare choices and support them in their intentions for future care (Wareham, et al.).

The Role of the Nurse

Literature on the nurses' role, attitudes and knowledge towards advance directives has been drawn from studies from Canada and the USA. No literature investigating the primary health nurses role specifically was found. However, available were studies of general nurses, home health nurses, oncology nurses and those working in elder care which inform this study and although not specific to primary health, role similarities provide an understanding into the primary health nurse. The literature chosen was considered relevant as their settings and services are often conducted in the community setting. Literature on the role of the primary health nurse is then conducted under its own heading in this section. Research

denotes that nurses are in a prime position to lead advance directive discussions as a result of the trust relationships they often have established with patients (Badzek et al., 2006; Jezewski et al., 2005; Mogg, 2006).

However, many studies have revealed nurses have large gaps in their knowledge about advance directives (Badzek, et al., 2006; Blondeau et al., 2000; Jezewski, et al., 2005; Pemberton, Storey, & Howard, 2003; Putman-Casdorph, Drenning, Richards, & Messenger, 2009; Westley & Briggs, 2004) particularly around the legalities of advance directives (Duke & Thompson, 2007; Putman-Casdorph, et al.; Scherer, Jezewski, Graves, Yow-Wu, & Xiaoyan, 2006). Duke and Thompson investigated practices of nurses in advance directive communication. They concluded nurses were mostly not involved (or only minimally involved) in advance directives, emphasising the need to clarify the nurse's role. They also found the nurse's level of education and confidence in advance directives may affect their ability to discuss them with patients (Duke & Thompson; Jezewski, et al., 2005). Studies investigating nurses roles and their attitudes towards advance directives agree administrative support and medical support is required for nurses to become more involved in advance directives (Duke & Thompson; Griffie, et al., 2004; Jeweski, Meeker, & Schrader, 2003; Jezewski, et al.).

A comparative study of 105 terminally ill patients revealed families with advance directives report less stress than families without them (Davis et al., 2005). This study was limited in its extrapolation in that it involved those of homogenous ethnicity. Others who chose not to be involved in the study for various reasons may have skewed the data. The overall recommendation from this was the need for nurses

from a variety of healthcare settings to provide opportunities to discuss end-of-life issues and advance directives, in an effort to decrease stress levels for terminally ill patients at a very stressful time (Davis, et al.). Moreover, health professionals need to respond to opportunities for communication or risk subjects becoming taboo (Griffie, et al., 2004).

According to Blatt (1999) health providers need to be comfortable with the concept of advance directives and their own personal values to facilitate advance directive discussion. Early research on the attitudes of Canadian nurses to advance directives discovered nurses have a positive attitude towards advance directives (Blondeau, et al., 2000), a finding congruent with later studies (Duke & Thompson, 2007; Jezewski, et al., 2005). Blondeau et al. concluded the positive attitude of nurses is rooted in respect for patient autonomy, belief in justice, the importance of relationships and the influence of place of work. They believe nurses will be called on to take a more proactive role in advance directive communication. This is supported by Douglas and Brown (2002), suggesting nurses need to be advocates for the patient in advance directives.

Findings from a questionnaire on nurses' perceptions about advance directives in an American community hospital revealed nurses need more education about advance directives (Ryan et al, 2001) Ryan et al.'s study also highlighted the need to educate the public, suggesting this be accomplished through various media. Furthermore, 55% of the nurses from that study suggested they had a responsibility to facilitate advance directive information. However, the findings are limited with less than half of the participants answering the open ended questions (Ryan et al.). A

study of 677 oncology nurses from the USA on what is needed to assist patients with advance directives also expressed the belief the public needs more awareness of advance directives to facilitate advance directive discussions (Jezewski et al., 2003). More importantly, a large majority of the participants believed advance directive discussions were part of their nursing role. One participant indicated that patients often feel more comfortable with nurses discussing their symptoms, problems and side effects implying nurses were ideally suited to the role. Others identified the importance of early discussions held before the patient's condition deteriorates as they are often the first contacts to whom patients' ask questions about their illnesses. Most participants indicated they needed education, time, and administrative support as well as environmental and institutional support to assist them in their efforts; all features commonly described in other studies.

A 12-month nurse practitioner advance directive intervention with 135 older adults living in a retirement community has led to further understandings in advance directive formulation (Resnick & Andrews, 2001). The study involved baseline interviews with 159 residents followed by a presentation on advance directives by a nurse practitioner. Pamphlets and handouts were given out to help the participants determine their personal values along with sample forms of advance directives and living wills. Each participant was then invited individually to meet with the nurse practitioner to discuss advance directives and to bring any paper work with them. The participants were interviewed for a second time 12 months after the initial interviews. A resulting success with this intervention showed a significantly increased number of completed advance directives, with an increase from 35% to 89%. The results of this nurse-led intervention supports similar research (Resnick &

Andrews) .

Thompson et al. (2003) explored interdisciplinary health professionals' (nurses, general practitioners and hospital doctors) views on advance directives. Results from this qualitative research using semi-structured interviews and focus groups showed support for advance directives as a way of honouring patient wishes and a belief that they assist when relatives have difficulty letting go. Importantly, the literature cautions against the possibility of coercion, documentation confusion and the removal of clinician discretion to let someone pass away without further intervention (Thompson, et al.).

Findings from a study to determine nurses' knowledge, attitudes and experiences in advance directives and examine predictors of advance directive discussions between nurses and patients suggest age and nursing experience do not correlate to advance directive discussions (Lipson, Hausman, Higgins, & Burant, 2004). This finding was thought to be related to a lack of knowledge and education, as well as the various job settings. A questionnaire was administered to 719 randomly selected nurses in the USA. The majority of the sample had cared for at least one patient with advance directives and those with this experience were more likely to have had advance directive conversations with patients. The study cautions against the interpretation of this point, as it was not known whether the discussion with or the caring for the patient came first. Most participants, however, had positive attitudes towards advance directives which in this study appeared to positively correlate with age (Lipson, et al.).

In contrast, an evaluation of nurses' knowledge, attitude, confidence and experience with advance directives conducted in the USA in a large teaching hospital revealed less positive attitudes to advance directives (Putman-Casdorph, et al., 2009). The participants were involved in a variety of inpatient and outpatient settings. The authors suggested this may reflect cultural attitudes at the time, as a contentious public issue on patients' rights had been in news headlines prior to the study. Nurses had slight to moderate confidence in dealing with advance directives, although an increased confidence and belief that advance directives are part of the nursing role correlated to increased experience with them. Again a lack of education was identified and related to a lack of confidence in advance directives. Limitations of the study included a 44% response rate to the questionnaire used, the study being conducted in only one hospital and the small sample size (Putman-Casdorph, et al.).

Badzek et al. (2006) undertook a study on advance care planning and home-health nurses' knowledge, comfort levels and experiences with this. Five hundred and nineteen nurses in the US responded to a questionnaire. Findings indicated that not only was there a lack of knowledge about advance care planning but those who perceived themselves to be more knowledgeable about such planning may be misinforming patients. For example, of the 20 factual questions asked relating to advance care planning; only 11 of the questions were answered correctly. However 73% of those who incorrectly answered these questions considered themselves to be knowledgeable about the topics asked. In general, the nurses were comfortable with the concept of advance care planning but believed the biggest barrier to engaging in this was reluctance of the patients or family to take part in the conversation (Badzek, et al.). Recommendations from this study included more education, knowledge and

support was required for the participants to become advance care planning facilitators.

A quantitative study by Zhou, Stoltzfus, Houldin, Parks and Swan (2010) in the eastern USA on the knowledge, attitudes and practices of 90 oncology advanced practice nurses (APN) differs from Jezewski et al.'s (2005) and Badzek et al.'s (2006) findings that nurses had limited knowledge. The study found APNs were moderately knowledgeable about advance care planning. Attitudes were generally positive to advance care planning; however the main barrier to advance care planning perceived by the APNs was the reluctance of the doctors, the patient and their families to become involved in these discussions. The limitations of this study include the small sample size, possible bias of self-report and the limited measures of knowledge and attitudes included in the scope of questioning (Zhou et al.).

Appropriate communication, practical improvements, and respect for patient autonomy and dignity are the focus for on-going end-of-life reform but more education and multidisciplinary (medicine, nursing and ethics) support is essential to foster this role (Murray & Jennings, 2005). The literature discussed in this section suggests nurses across a variety of settings need to be more knowledgeable about advance directives. The majority of these studies resulted in commonalities; a positive attitude to advance directives, a lack of knowledge – particularly legal knowledge – around advance directives, and the need for education, support, more experience and confidence to be involved effectively in advance directive discussions. Samanta and Samanta (2010) see this involvement in advance directive discussions as the nurse facilitating empathetic discussions about goals of treatment

and care, and possibly as a referral agent to agencies to formalise advance directives or appoint a power of attorney. Furthermore, they believe the nurse's role is also to treat incapacitated patients in their best interests, work and communicate with the multidisciplinary team and patient families, and record any decisions made. The nurse's role may include referring disputed advance directive cases to the courts (Samanta & Samanta). These parameters align with the NZNO position on advance directives for New Zealand nurses.

The role of the nurse in New Zealand

There is a paucity of New Zealand literature around advance directives, especially in regard to nurses. In September 2010, the New Zealand Nurses Organisation (NZNO) issued their first position statement for: The role of the nurse in the delivery of end-of-life decisions and care. Advance directives are defined by the NZNO as “a written or oral directive –

- (a) By which a consumer makes a choice about a possible future healthcare procedure
- (b) That is intended to be effective only when he or she is not competent” (New Zealand Nurses Organisation (NZNO), 2010, p. 4).

Relevant points covered in the NZNO (2010) mission statement surrounding advance directives include the nurses professional and legal obligations related to informed decision making and the legal and ethical duty nurses have to respect the individual's wishes. The NZNO also supports the right for individuals to refuse treatment as long as the nurse is present when the advance directive is signed and the nurse considers the consumer has received adequate information, understands the directive and acts voluntarily. Further points made in the NZNO mission statement are

located in the appendices (see Appendix F). One recent piece of research completed in New Zealand indicates the nurses' views on end-of-life care align with the NZNO mission statement guidelines.

A qualitative study using semi-structured interviews was conducted in 2006 at Dunedin Hospital on nurses' view points on end-of-life issues (McLennan, Celi, Gillet, Penney, & Foss, 2010). A total of 16 nurses from differing specialties were interviewed. Findings indicated nurses were willing to become involved as a team participant in discussing end-of-life areas in clinical decision making. Moreover, the importance of family involvement (if the patient agrees) was deemed as significant in making decisions such as withdrawing or limiting life-sustaining treatment. The partnerships between the nurse, the patient, family and doctors were considered important in alleviating patient stress which often results from a lack of communication and understanding of tests and interventions happening to the patient.

Wareham et al. (2005) further suggest New Zealand nurses are in a strong position to initiate advance directive communication. Knowledge of self, competency within the scope of practice and a belief that nurses need to act on behalf of the consumer are prerequisites to facilitating advance directive conversations. Underpinning this is an awareness of the legal and ethical complexities involved and a knowledge of when and to whom to refer patients to (Wareham, et al.). Further to this, Wareham et al. identified the importance of advance planning with well patients before they become incapable of making such decisions, thus enhancing patient autonomy and end-of-life care. Recommendations from this study identified the importance of the nurse in this role and the need for further research, particularly in

relation to primary health nurses.

The role of the primary health nurse

As far back as 1992 the nurse practitioner was recognised as suitable for facilitating advance directives in primary care (Towers, 1992). Adequate educational preparation for the role was considered essential, along with the nurse having an awareness of his/her own values and attitudes, and the impact these may have on influencing the patient. Furthermore, it was suggested all patients in primary care should be offered the opportunity to develop advance directives under guidance of the provider. Although advance directives are an individual procedure, the sharing of information with family members was also encouraged (Towers).

At a later date, Duffield and Poszamsky (1996) conducted a study in a private family practice in the USA of patients over 21 years old who did not have an advance directive. The aim of the study was to determine if discussions held about advance directives followed by the distribution of easy to use advance directive forms, would increase advance directive uptake. One hundred and ninety five patients were invited to discuss advance directives and were given the advance directive form resulting in 88 patients completing advance directives. The results of this study supported Towers' (1992) findings suggesting the primary care setting is effective in advance directive communication, while further suggesting all adult patients be given the opportunity to discuss them. They concluded from this study that the setting, the process, the relationship between the patient and primary care health provider were key to completing advance directives. The study was limited by sample size and restriction to one rural primary care office (Duffield & Poszamsky).

More recently, the Respecting Patient Choices programme – used in both the USA and Australia – provides a framework and set of skills to assist nurses with initiating conversations around advance care planning (Mogg, 2006). Mogg suggests primary health nurses have a vital role in advance care planning as they see people in the community in early stages of disease, when these topics need to be raised. Similarly an evaluation conducted in 2009 of the PPC advance statement document in the UK has demonstrated its usefulness in the community setting (Newton, et al., 2009). More people are dying in their preferred place of choice, particularly when the advance statements are initiated by generalist community nurses rather than palliative specialists or hospital teams. Furthermore it was found that relationships improved between staff and their patients with the introduction of the document and nurses becoming more proactive in their care. However this evaluation was limited by a lack of data collection prior to the beginning of the project and the absence of case studies completed but not reported on (Newton, et al.).

Auer (2008) found, in her case study, end-of-life discussions are integral to chronic disease management and need to be initiated early in the disease process. As chronic disease accounts for a large proportion of primary care practice, Auer suggests this planning becomes routine practice in primary health, as regular visits lend themselves to initiate discussions and allows time for the patients to consider their options. This case study showed opportunities for a skilled nurse to be an advocate and support-person for the patient in advance directive discussions. By determining the patient's goals and values the nurse may act as a go-between for the patient and general practitioner (Auer). Conroy et al. (2009) support this finding and believe specialist nurses are able to successfully lead advance care planning

discussions.

Primary healthcare in New Zealand has been described as the focus for the future, with nurses playing a significant role in the successful delivery of care (Docherty, 1996). Underpinning primary health nurses in New Zealand is the Primary Health Care Strategy, 2001, which aims to widen the range of population focused services. This requires well-trained primary health nurses with common generalist knowledge and skills, as well as advanced skills in particular areas (Ministry of Health, 2001b). As suggested in the literature, advance directives and advance care planning are suited to primary health. There is an emphasis on the need for nurses to be knowledgeable about informed decision making in order to facilitate the completion of advance directives as routine practice in primary health (Duke, Thompson, & Hastie, 2007; Maxfield, et al., 2003). Specialist nursing skills could be developed to meet this need in the primary health environment.

Advance Directives in the Primary Health Environment

A number of researchers suggest emergency end-of-life decisions should not be made while under pressure or during a crisis (Maxfield, et al., 2003; Pugno, 2004; Putman-Casdorph, et al., 2009). They contend that formulating advance directives in acute settings is unfavourable and are best completed in primary care settings. This idea is supported by other literature suggesting discussions on advance directives should begin in a primary health setting while the patient is healthy or in early stage disease (Conroy, et al., 2009; Pugno; Putman-Casdorph, et al.; Resnick & Andrews, 2002; Sutton & Sam, 2009; Westley & Briggs, 2004).

Discussions about advance directives should be a process rather than a single event (Conroy, et al., 2009; Jackson, et al., 2009; Tamayo-Velazquez et al., 2010). These types of discussions with chronically ill patients are believed to increase their satisfaction with their end-of-life care (Conroy, et al.; Pugno, 2004). Maxfield et al. (2003) argue patients need time to consider their core values and, suggest when healthy patients discuss these with a primary care health professional. Other researchers concur with this and suggest a collaborative approach with the doctor, patient and family over a length of time can guide the patient and health provide in appropriate decision making in developing an advance care plan (Crane, et al., 2005; Pugno). Tamayo-Velazquez et al. recommend passive material is distributed with this. They also point out these discussions need to be reviewed over time, especially when there is a change in health or personal circumstances. However, caution is required to ensure formal advance directive documentation does not overshadow this communication process. They believe the ultimate goal of the advance directive is to reflect the patient's values and goals, and protect their autonomy and right to participate in their own decisions when incapacitated (Maxfield, et al.).

Similarly, other research has shown an increase in patient satisfaction with primary care providers when the topic of advance directives was introduced (Pugno, 2004; Tierney et al., 2001). Conversation, on advance directives, initiated during general practice consultations with 686 elderly or chronically ill patients in a study in the USA, resulted in increased satisfaction with care providers (Tierney, et al.). Time pressure may discourage this communication, however the authors of the study believe these discussions should occur with a trusted primary care provider when patients are well and able to explore end-of-life issues (Tierney, et al.). The

longitudinal relationships provide the context for continuity of care in these discussions which may easily be incorporated into health maintenance consultations (Pugno).

Likewise, Ramsaroop et al. (2007) who conducted a literature review on articles designed to increase uptake of advance directives in primary care found interactions over multiple visits yielded the most significant results, while patients with acute medical problems were less receptive than those in for a general health check. Furthermore, the authors suggest lack of continuity of care in large primary centres may hinder advance care discussions. This aligns with the idea patients are more willing to discuss advance directives with someone with whom they have an ongoing, long-term relationship with (Hanson, Earp, Garrett, Menon, & Danis, 1999; Munday, et al., 2007; Ramachandran, 2008; Ramsaroop, Reid, & Adelman, 2007; Schaden, Herczeg, Hacker, Schopper, & Krenn, 2010).

More recently however, Sudore and Fried (2010) argue advance care planning should aim to prepare patients and families to work with the health provider to make the best in-the-moment decisions. Primary care nurses could help prepare patients and families, by establishing goals and values to assist in decision making, should the need arise (Sudore & Fried; Sutton & Sam, 2009). Advance directives are one piece of information to be used in the decision making process. This process reduces the likelihood of patients making broad or premature decisions from incomplete information to prepare for in-the-moment decisions (Sudore & Fried).

Advance directives in primary health in New Zealand

Primary health encompasses first level care services with the general practitioner and/or primary health nurse, pivotal to the oversight of care provision. Continuity of care in primary health is regarded as important in developing relationships between the individual, family and provider (Ministry of Health, 2001b). These relationships are conducive to advance directive discussions as formulating advance directives is seen as a process of communication rather than a single event (New Zealand Medical Association, 2004).

A recent initial evaluation of a six month intervention consisting of implementing community programmes, medication review, nursing education and advance care planning to support age related residential care suggested advance care planning may be more appropriate for elder adults who live independently in the community. This evaluation was undertaken in one facility consisting of a rest home with 46 residents and hospital level care for 50 residents. Nurses and general practitioners were offered training in a formal process of advance care planning. All of the nurses at the facility participated in this training. Interview schedules were used to collect data from senior management (some of whom were registered nurses), the geriatrician, general practitioner, registered nurses and a convenience sample of enrolled nurses and care givers at the facility. No advance care plans were made over the six months. However this was related to a delay caused by legal review of documentation and/or other pressing health challenges faced by residents. Staff suggested the cognitive levels of the patients were inadequate although this was not supported by the geriatrician or social worker involved. Concerns regarding the time required to work with a resident and the potential of undermining the residents' sense of security by

signing an advance document during this phase were also expressed by staff (Sankaran et al., 2010).

Conclusion

There are many issues related to the primary care nurse's role in advance directives. As mentioned earlier, little information was found about the primary health nurse and advance directives. Studies investigating advance directives situated in primary health were reviewed, however no literature specifically examining the primary health nurses role in advance directives were found. Related nursing specialty studies such as oncology, elder care or home health nursing were identified regarding the nurses' role and advance directives. These studies were critiqued to provide the context for this study on the primary health nurse's role in advance directives. Generally, the literature suggests that nurses are integral to advance directive discussions particularly due to their well-established relationships with patients. Findings suggest most nurses have positive attitudes toward advance directives. However gaps were identified in nurses' knowledge, education and support in advance directives.

Advance directives are now recognised as a process of communication as opposed to the signing of a form. Multiple conversations between health providers and patients are vital to facilitate this communication in order to determine patient values and needs.

As multidisciplinary teamwork plays an important part in patient care, research contends that nurses are pivotal to advance directive discussions. With primary care

becoming increasingly recognised as having a leading role in advance directives the role of the primary health nurse is coming under scrutiny. This study being conducted on advance directives serves to examine the role of the primary health nurse. The next chapter explores the theoretical lens through which this research was viewed.

Chapter 3: Theoretical Framework

Introduction

A theoretical framework is considered a map that helps determine the research problem, questions, data collection and analysis strategies of a study. It is derived from the orientation or stance the researcher brings to the study and frames the lens through which the world is viewed (Merriam, 1998). Establishing a framework is achieved either through a careful literature review, which may reveal possible theoretical approaches, or from the orientation of the research discipline itself (Crabtree & Miller, 1999; Merriam; Yin, 2009). Yin suggests a theoretical framework is important in designing a case study, further suggesting the theoretical orientation becomes the main vehicle for understanding the results. The theoretical framework for this study, Watson's Theory of Human Caring, was derived from the nursing discipline.

Watson's Theory of Human Caring

Watson's Theory of Human Caring underpinned this qualitative case study. Watson's Theory of Human Caring originated in 1979 from the philosophical writings of Dr Jean Watson, an American scholar (Jesse, 2010). Modern theoretical approaches to nursing were underpinned by problem based nursing practice, homeostasis and adaptation. Watson's postmodern approach incorporated into her theory moved beyond this and redefined the nursing paradigm. This led to a more holistic, humanistic approach with emphasis on harmony, interpretation, and self-transcendence. Watson's writings on human caring have been aimed towards educating nursing students and providing the epistemological basis for their praxis

and research direction (Jesse).

According to McGee (2005), the concept of care forms the focus of all nursing activities. It is a multifaceted concept, influenced by individual needs, personal circumstances, societal expectations, health policies and professional standards (McGee). Watson (2009) suggests that caring is a worldview, is intentional and is a way of being. Caring has no time-defined path and manifests itself from the moment we attend to self and patient within the context around us (Sitzman, 2002). Watson believes that nursing care is developed through a combination of science and the humanities (Jesse, 2010), underpinned by a humanistic (Current Nursing, 2010; Rafael, 2000) and existential conceptualisation of the human being (Rafael). Her theory takes into account the patient and nurse (Cara, 2003; Rafael). It provides a framework for addressing the mind, body and spirit of the nurse and patient simultaneously during interactions (Sitzman), without compromising the wholeness of the person (Rafael). The goal of this theory is to preserve dignity and humanity in healthcare in facilitating harmony between the mind, body and soul (Cara; Jesse).

Watson's theory calls for nurses to go beyond the clinical focus, tasks, and procedures used in the workplaces, known as the "trim" of nursing. She describes the "core" of nursing as those characteristics of the nurse–patient relationship that result in a therapeutic outcome from the transpersonal caring process. Understanding these concepts enables the theory to be applied to any specialty of nursing (Jesse, 2010). Sitzman (2002), an American nurse scholar, suggests changes in their healthcare systems have increasingly seen the nursing role as performing technical tasks, or "trim", measured in objective and often monetary terms (Sitzman). As patient acuity

and complexities increase, nurses are required to maintain their core values and practice of caring (Cara, 2003) to provide effective care. This may cause frustrations for the nurse if her practice is not congruent with her own moral ideals (Cara). Caring for each other in stressful times has been identified as essential to keep staff energised and sustain an environment of caring for patients (Carter et al., 2008). It is not only important to attend to the “trim,” but also the “core” of nursing, including multi-level interactions with the patient, self-reflection and personal growth (Sitzman). The “trim” and the “core” combine to become a fluid “whole of nursing practice” (Sitzman), and are intrinsic to Watson’s theory.

The major components of Watson’s Theory of Human Caring are the ten carative factors, the transpersonal caring relationship and the caring occasion/moment (Watson, 2001). Each of these three components is briefly described below.

Carative factors

Watson’s theory consists of ten carative factors described as:

- formulation of humanistic–altruistic system of values;
- installation of faith and hope;
- cultivation of sensitivity to self and others;
- development of a helping–trust relationship;
- promotion and acceptance of the expression of positive and negative feelings;
- systematic use of scientific problem-solving method for decision making;
- promotion of interpersonal teaching–learning;

- provision for a supportive, protective and corrective mental, physical, socio-cultural and spiritual environment;
- assistance with gratification of human needs; and
- allowance for existential–phenomenological forces (Jesse, 2010, pp. 95-96).

Each factor has a phenomenological aspect relating to the individuals involved in the nurse–patient relationship (see appendix A for a detailed description). These factors aim to generate self-knowledge, self-reverence, self-healing and self-care in the patient while at the same time enhancing self-knowledge and growth for the nurse.

This occurs as a result of human-to-human caring processes and actions (Jesse, 2010). Over time, Watson expanded these carative factors into clinical caritas¹ processes (see appendix B), which have a greater spiritual dimension (Cara, 2003).

These caritas processes offered ways for the carative factors to be considered (Jesse) in a way that is more fluid and contemporary (Watson, 2001). For example, carative factor two, the instillation of faith and hope is characterised by the nurse being authentically present during an encounter with the patient. During this time the nurse is able to sustain his or her deeply held belief systems and subjective life-world of self, and those of the patient. Intertwined with these processes are the transpersonal caring relationship and the caring occasion.

The transpersonal caring relationship

Watson’s humanistic and existential concepts of the person underpin the transpersonal caring relationship where both the nurse and the patient are valued and regarded as important (Rafael, 2000). The transpersonal caring relationship is foundational to Watson’s theory (Jesse, 2010). It is based on the nurse’s moral

¹ Caritas is a Latin word meaning “cherish, to appreciate, to give attention”(Jesse, 2010, p. 94)

commitment in protecting and enhancing human dignity and the nurse's caring consciousness. This is communicated with the intention to heal the patient and preserve the embodied spirit (Cara, 2003; Pipe, 2008). A human-to-human connection occurs in which both people are influenced by the connection (Watson, 1999). The relationship goes beyond the nurse's own ego in order to reach the patient's deeper spiritual connections in promoting patient comfort and healing. The caring consciousness of the nurse is intentionally communicated to connect on a deeper spiritual level and to protect, enhance and preserve the person's dignity, wholeness and inner harmony (Watson, 2001). The transpersonal relationship allows the nurse to enter into the experience of the patient, and the patient to enter into the experience of the nurse. It includes a metaphysical and spiritual dimension that goes beyond time, space and the physical body (Watson, 1999). Transpersonal caring also nurtures a healthy relationship with self thus providing further impetus for the nurse to focus outwardly and more effectively over time (Pipe).

The caring occasion

The caring occasion occurs when the nurse and the patient connect through the totality of their human experiences at a given point in space and time (Watson, 1999, 2001). Watson argues that the nurse must be aware of his or her own consciousness and having a genuine presence in a caring occasion with the patient. The caring occasion involves an action and choice by the patient and the nurse, offering them an opportunity to decide how to be in this relationship in the given moment (Watson, 1999, 2001).

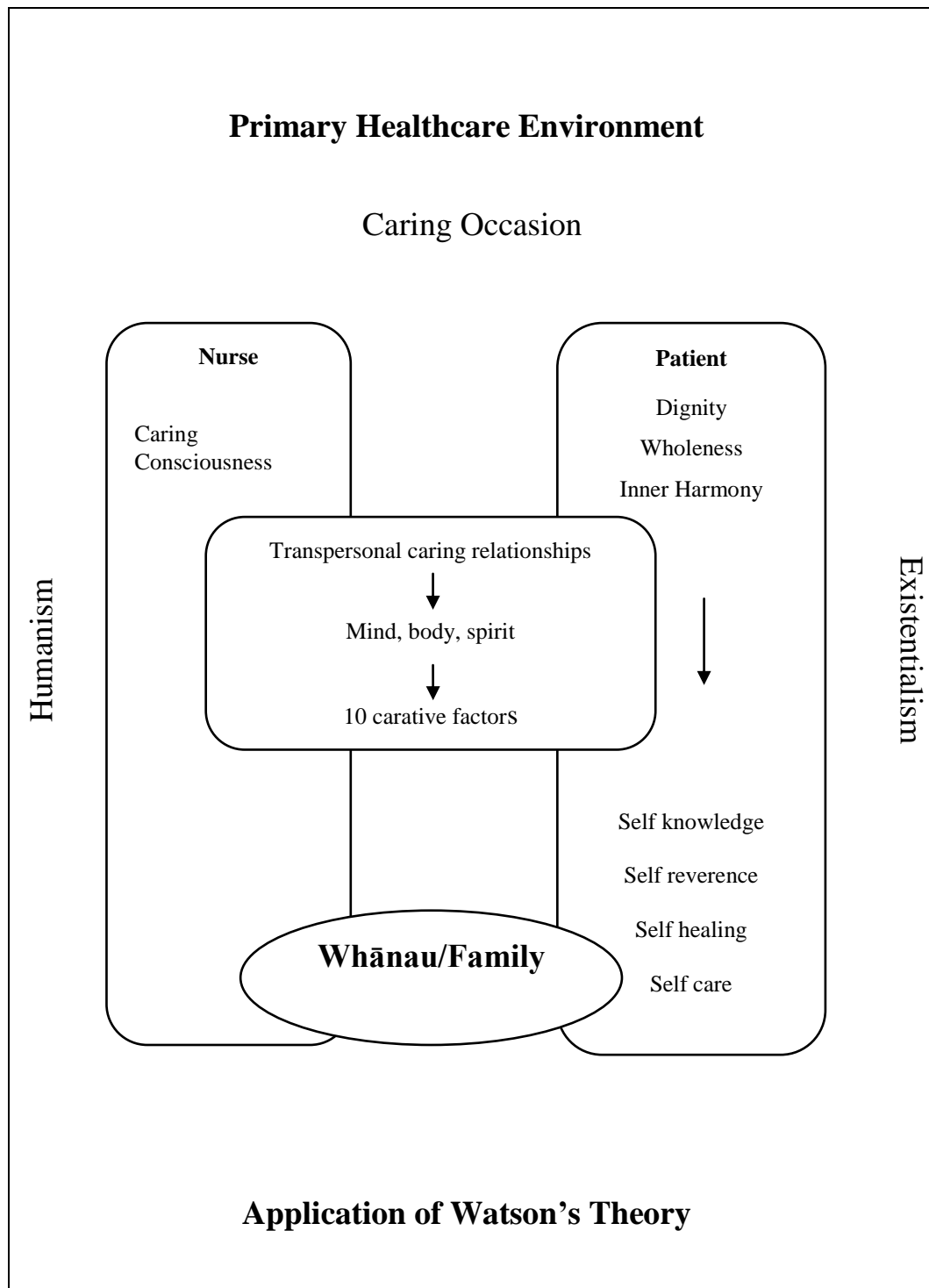
The importance of the caring occasion is reflected in the following study on primary care nurses. Moore (2002) investigated patients' perceptions of caring and non-

caring nurse practitioners in primary care. Findings showed the importance patients placed on the nurse having a genuine presence during their interactions. Caring and caring behaviours such as the clinical caritas processes were found to be central to the nurse–patient relationship and provision of nursing care. Moore found that caring behaviours lead to an improved focus in the provision of care and greater patient satisfaction. When nurses demonstrated caring behaviours, patients felt more secure in their care; this suggested caring behaviour can overshadow the technical and physical care in the primary care setting (Moore).

Applying Watson’s Theory of Human Caring to This Study

My interpretation of Watson’s theory in the primary healthcare environment is presented in Figure 3.1 as a schematic illustration. The caring occasion between the nurse and the patient is manifested in the primary health environment using humanistic and existential practices. The nurse consciously and authentically acts to create transpersonal caring relationships using carative factors to develop nurse–patient therapeutic relationships. This caring consciousness, transpersonal connection and authentic presence is directed to the patient and their whānau/family. It is through these connections that the patient sustains his or her dignity, wholeness and inner harmony that enables the nurse and the patient to grow in their self-knowledge, self-care, self-reverence and healing. These characteristics are essential in enabling the nurse to advocate for the patient and support patients’ through informed decision making processes required for advance directives in the primary health environment.

Figure 3.1 Schematic interpretation of Watson's Theory of Human Caring



Summary

This chapter described Watson's Theory of Human Caring, the theoretical framework used for this study. The framework was derived from the nursing discipline. Essential concepts of Watson's theory – carative factors, the caring occasion and the transpersonal caring relationship, were used to guide every stage of the research process. A discussion of the methodology used in this study is presented in the following chapter.

Chapter 4: Research Design

Introduction

This chapter describes the research approach used for this study on the primary health nurse's role in advance directives. I describe the rationale for using a qualitative case study design and outline how this method was used in the sampling process, recruiting participants, data collection and analysis. Ethical and cultural considerations and trustworthiness are included in the discussion. The overall aims and objectives of this study are discussed to uphold the rationale of the research question. The purpose of this qualitative study was to uncover primary health nurses' knowledge, experience and attitudes about the primary health nurse's role in advance directives.

Overall Study Design

The research approach is determined by the focus of the research question. This includes the purpose of the study, the information required to answer specific questions and which approach is best suited to meet these requirements (Denzin & Lincoln, 2005; Yin, 2009) .

A qualitative approach was chosen to uncover primary health nurses' knowledge, experience and attitudes about the primary health nurses role in advance directives. Qualitative research endeavours to uncover the experience of a phenomena or a person (Merriam, 1998; Nieswiadomy, 1993), and is used across multiple fields, disciplines and topics (Denzin & Lincoln, 2005). Qualitative research is based on world views and involves understanding the socially constructed nature of the world. Therefore qualitative research is unable to be separated from time, values, location and

expressions of the person (Holloway & Wheeler, 2010). It is not an exacting approach but uses a variety of structured approaches and interpretive strategies to create understandings in different ways (Denzin & Lincoln; Holloway & Wheeler). These approaches enable the researcher to make an individual's world visible to others and is considered to be the most suited methodology in exploring the subjective reality of the individual (LoBiondo-Wood & Haber, 2010).

Qualitative inquiry may follow structured approaches such as sampling, data collection and analysis that are theory based. Theories may be used in different ways in qualitative research (Creswell, 2009). Firstly, theories can offer wide-ranging explanations of behaviour and attitudes. Secondly, a theoretical lens or perspective may be used to indicate where the researcher positions him or herself in relation to the study, providing a guide through which questions, data collection and analysis are shaped (Creswell; Merriam, 1998). Thirdly, a theoretical lens can be used as an endpoint, where an inductive process is used to build on the data analysis and broad themes to produce a generalised theory (Creswell). Seidman (2006) suggests theory should stem from words, rather than words be force fitted into them. However, Seidman does contend that it would be naïve to suggest research can be theory-free, as theory has a role in explaining connections. Watson's Theory of Human Caring, the theoretical framework chosen for this study, positioned me as the researcher and as a nurse, and provided a lens through which my questions, data collection and analysis were constructed.

Most qualitative research takes place in naturalistic settings where the normal day-to-day experience of the participant occurs (LoBiondo-Wood & Haber, 2010). A qualitative case study method was chosen to provide a rich and in-depth description of

the phenomenon and to reflect the views of the primary health nurses who participated in this study.

Case Study

My interest and experience in clinical nursing practice in end-of-life care offered me insight into the effect of advance care planning and a desire to learn more about it. Case study researchers are often familiar with the topic they choose to study (Holloway & Wheeler, 2010). This research approach was chosen for this study to investigate the phenomena in context (Holloway & Wheeler), to create a rich description and in-depth understanding into this case study (Stake, 1995). Case studies explore in depth a contemporary phenomenon within its real-life context particularly when boundaries between the phenomena and context are unclear (Yin, 2009).

For this case study I wanted to find out what role primary health nurses had in advance directives. This type of inquiry favours the use of a case study (Yin, 2009).

The case study can further be defined as particularistic, descriptive and heuristic in nature (Merriam, 1998). Particularistic means the study focuses on a particular event, situation, programme or phenomenon. Descriptive refers to rich description achieved through the study processes and heuristic is where the aim is to enlighten the readers' understanding of the phenomenon (Merriam). The case study is not designed to provide generalisations or representation but rather create understandings into a phenomena under study (Stake, 1995).

The case study is iterative in nature (Crabtree & Miller, 1999) requiring the researcher to remain adaptive and flexible in adjusting to new situations (Yin, 2009). It is used for in-depth research into a single unit or a small number of units (Polit & Tatano Beck, 2006). The case study approach has explicit boundaries (Holloway & Wheeler, 2010) known as a “bounded system” (Creswell, 1998; Holloway & Wheeler). Along with boundaries, a case study has a specific focus and is bound to context (Creswell; Holloway & Wheeler; Merriam, 1998; Polit & Tatano Beck). Case study boundaries are clarified in terms of questions asked, the unit of study, the setting, data sources used and persons involved (Holloway & Wheeler).

A case study’s strengths include the ability to offer insights into phenomena and illuminate to readers an understanding of the case (Yin, 2009). The five components of a case study as described by Yin are

- 1) the study’s questions;
- 2) propositions, if any;
- 3) the unit(s) of analysis;
- 4) links between the data and propositions; and
- 5) criteria for interpreting the findings.

Similarly, Stake (2005) suggests the major conceptual responsibilities of the case researcher include bounding the case, selecting phenomena or themes to emphasise, seeking patterns in the data, triangulating key observations, selecting alternative interpretations and developing assertions about the case.

Defining and classifying the question as a case study is essential to conducting the study. The research question and objectives were:

The research question

What role do primary health nurses have in advance directives?

Research objectives

- Explore and describe primary health nurses' general knowledge and attitudes relating to advance directives.
- Describe primary health nurses' experiences with advance directives.
- Describe the primary health nurse's role with advance directives in primary health.

Study propositions

Study propositions are identified to provide the direction for which aspects are to be examined within the scope of the study (Yin, 2009). This provides a solid foundation for the data analysis (Yin). Two propositions were identified through the literature and my practice experience; these propositions informed my analysis: 1) primary health nurses currently do not have a role in advance directives; and 2) primary health nurses believe that advance directives can promote effective-end-of-life care. The propositions identified informed the basis of my data analysis (Stake, 1995).

In case study research, the unit of analysis or case is defined. The case may relate to an individual, an event, a community, location or other entities (Holloway & Wheeler, 2010; Yin, 2009). For this study, the primary health nurse was defined as the primary unit of analysis. When more than one primary unit of analysis is studied it is known as a multi-case study (Yin). Findings from multiple case studies are often considered to generate a greater understanding than single case studies (Yin). This study included 13 participants and was therefore a multi-case study using a number of cases to inquire into a phenomenon (Stake, 1995). Individual cases may or may not have similarities or common characteristics (Holloway & Wheeler; Stake). There were

commonalities and differences within each case in my multi-case study. Commonalities include the fact that all participants were primary health nurses, involved in delivering first contact primary care. However, there were differences in that each individual came from differing settings making their context unique to their experiences and understanding of advance directives (see Appendix G for further context descriptions). Thirteen different cases enabled a more in-depth understanding to be achieved in this case study. The boundaries of this case study are illustrated in table 4.1 (p. 57).

Entering the Field

In the early stage of my research process I wanted to ensure my rationale for conducting this study was sound. A gap in literature and practice were evident however I needed to be sure the focus was important and relevant to our time (Holloway & Wheeler, 2010). In an effort to further support my rationale I organised a number of consultation meetings with a wider community of health providers I considered important to my research. I consulted with academics, the local primary health nursing director, the local hospice director and other medical and nursing colleagues. These meetings were conducted to explain my research, and to seek support and understanding from the wider community. The relevance and importance of this study were confirmed at these meetings. Further consultation meetings were arranged to ensure that cultural considerations would be taken into account.

Table 4.1.

Boundaries of this case study

Boundaries of a case study	Boundaries of my case study
Unit(s) of study (multisite)	Primary health nurses
Specific focus	The primary health nurse's knowledge, experience and attitudes about the primary health nurse's role in advance directives
Questions	What role do primary health nurses have in advance directives?
Setting	General medical practices or Māori health providers that provide primary healthcare in one province in New Zealand
Data sources used	Interviews, literature/documentation and observation

Cultural Considerations

The Treaty of Waitangi and Māori health and cultural safety are principles reflected in the Nursing Council's standards. These are of paramount importance, as research conducted from 2000–2005 suggests Māori providers are increasing access to healthcare for Māori (Robson & Harris, 2007). Cultural safety (kawa whakaruruhau) guidelines were originally introduced by Irihapeti Ramsden in 1991 and further

developed in 1996. They provide guidelines to ensure people receive nursing services related to all that makes them unique (Te Kaunihera Tapuhi o Aotearoa Nursing Council New Zealand, 2009). Cultural safety is defined as “the effective nursing practice of a person or family from another culture, and is determined by that person or family” (Te Kaunihera Tapuhi o Aotearoa Nursing Council New Zealand, 2009, p. 4).

Research Guidelines for both Māori and Pacific communities have been developed by the Health Research Council (Hudson & Russell, 2009). Allowing for both Western and Māori ethical concepts ensures cultural safety (Hudson & Russell). I used the Treaty of Waitangi guidelines of partnership, participation and protection to show respect to ethical issues important to the three Māori participants in my study and Māori in general. The meanings of these guidelines (in relation to research) are illustrated in table 4.2 (p. 59) and are adapted from Hudson and Russell.

Initial consultation was held with the Māori Health Manager at the local District Health Board (DHB) where I outlined the study. The study met the primary ethical principles of the “Te Ara Tika” draft in relation to Māori research. These principles include whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility) and mana (justice and equity) (Hudson, et al., 2010). The Māori Health Manager indicated his support and introduced me to other Māori health providers who were able to assist in accessing the population required for the study. It was agreed the results be presented at the end of the study.

Table 4.2.

The Treaty of Waitangi Guidelines

The Treaty of Waitangi Guidelines	
Partnership	Includes recognition of Māori groups as partners in research and respect for cultural knowledge and traditions. Respects the principles of Rangatiratanga and Tikanga Māori.
Participation	Includes Manawhakahaere over the research process by validating Māori concepts, incorporating Māori values and goals and involvement of Māori participants.
Protection	Includes actively protecting Māori rights and Mātauranga Māori and ensuring tangible benefits may be realised in an equitable manner and used to gain maximum health outcomes for Māori.

The study was also outlined to the Māori health co-ordinator at the local primary health organisation (PHO) (see Glossary p. 213). She also indicated support and again it was agreed the results be shared at the end of the study. In a second meeting I invited her to oversee the study to ensure protocols and cultural safety be maintained over the duration of the study. This involvement was sustained and met the principles of partnership, participation and protection. Hudson and Russell (2009) suggest involvement may include assisting with analysis and/or subsequent dissemination of results.

Discussions were also held with the Chief Executive Officer at the local Pacific Health Services Trust. The Trust is a non-clinical provider, giving a valuable wrap-around service to Pacific people in the small province. The Trust accesses nurses from the local hospital who provide care in the community. The intent of this study was to be inclusive of Pacific Health but this was complicated by the criteria that nurses needed to be working in primary health at the first point of contact. I was unable to access participants that met this criterion, as although a community service was provided to the Pacific population in the province, Pacifica nurses were accessible only through secondary services. Of further importance to the Pacific population is the preference to be grouped according to the country of origin, such as Tonga, Samoa, Fiji and other islands in the Pacific, instead of under Pacific Health. This creates a diversity of cultural commonalities and differences (Ministry of Health, 2008), which need to be considered in conducting research effectively and ethically; this aspect of research ethics was strongly relayed to me during the consultation process.

Ethics Approval

Following consultation with the wider community, ethics approval was sought from the Central Regional Ethics Committee. Guidelines from the Operational Standards for Ethics Committee (2006) document were followed. An expedited ethics approval was lodged as it was deemed an observational low risk study (Ministry of Health, 2006). Approval was granted 3 July, 2010 [CEN/10/EXP/29 3 July 2010] (see Appendix C).

The principle of non-maleficence was followed (Holloway & Wheeler, 2010), with research questions designed to minimise potential psychological or emotional harm

to participants. The research was undertaken in a way that respected the rights, culture and privacy of all concerned. Informed consent was obtained after a full explanation of the research purpose, methodology, timeline, and expectations of the researcher and participant was given. Time was allowed for the potential participants to reflect on this explanation, and was followed with a phone call to determine if further information was required before consent was sought.

The consent form (see Appendix H) assured participants of anonymity and confidentiality at all times. A pseudonym was used so participants were non-identifiable, and all information was kept in a locked cabinet or password protected computer file accessible only to me. As a senior primary health nurse myself, I was mindful that some potential participants could be nursing peers known to myself, so took particular care not to coerce them in any way to protect their vulnerability. I was not in any senior capacity to any potential participants. I knew a few of the participants by name only or from a nursing professional standpoint. The process involved in selecting the population is discussed in detail under recruiting participants.

Sampling

Purposive sampling is generally used in a case study approach (Creswell, 1998; Holloway & Wheeler, 2010; LoBiondo-Wood & Haber, 2010; Merriam, 1998) and was used initially in this study. This was determined by my purpose to understand and gain insight into the case or the primary health nurse's role in advance directives. No sample size was set as the aim was to gather information until data saturation occurred with no new ideas introduced (LoBiondo-Wood & Haber). I elected to study senior nurses from

primary health, employed in general practice or as a Māori health provider. I believed senior nurses would have the most experience and knowledge about the role of the primary health nurse in advance directives. To access this population, inclusion criteria were developed as follows:

- Senior registered nurse (five plus years' experience as registered nurse)
- Worked in general practice as a registered nurse for 12 months or more

or

- Worked as a Māori health provider as a registered nurse for 12 months or more
- English speaking

Exclusion criteria were:

- Nurses working in all other primary health areas, such as elder care, hospice, district nurses and other specialties
- New graduates working in primary health
- Registered nurses with less than 12 months of experience in primary health

Recruiting Participants

A list of all general practices in the province was obtained from the local Primary Health Organisation (PHO) (see glossary p. 213). Not all general practices are members of the PHO and those were identified through the phonebook and local knowledge. This was important to ensure all potential participants were given the opportunity to participate in this study to reduce possible biases and ensure sound methodological recruiting processes were followed. I telephoned all practices to request the name of their nurse manager or most senior nurse. I encountered informal gatekeepers, such as receptionists and practice managers, when trying to gain access to the names of potential participants. A gatekeeper is described as someone who controls

access to the participants (Seidman, 2006). After obtaining the names of the potential participants from the receptionist or practice manager, I sent information to all of their general practice managers (see Appendix I). This was done out of courtesy, to inform them of the research, and give the practice managers the opportunity to ask any questions. This provided transparency in the process of accessing participants. A personalised letter of information and invitation was concurrently sent to each identified nurse, inviting each to participate in the research (see Appendix J). A consent form to participate in the study and self-addressed stamped envelope was included (see Appendix H).

A directory of the Māori health providers was obtained from the PHO, with further information obtained from the District Health Board (DHB). Following consultation with the PHO Māori liaison coordinator it was decided initial consultation should occur face-to-face with an identified senior person, to engage their support. Senior staff from the PHO and DHB assisted in identifying the Māori health providers and the appropriate person to consult with in the first instance. I telephoned three out of town Māori health providers and visited the locally based providers to introduce myself and outline the study. Tone, conciseness, friendliness, purposefulness and flexibility in approach to gatekeepers and potential participants can enhance or weaken a contact visit or phone call (Seidman, 2006). Being aware of the importance of these implications determined how I made the initial approach and laid a foundation for mutual respect. The information sheet for practice managers and information/invitation sheet, consent form and envelope for the nurse was emailed or given to the identified senior person. These senior people decided who they believed would be most appropriate as potential

participants and provided these individuals with the information and an invitation to participate.

A total of 29 participants were invited to take part in the research. A period of seven to ten days was allowed for the invited participants to reflect on the invitation. I then followed up with a phone call to the named general practice nurses or identified senior person at the Māori health provider to determine if any further information was required. Ten primary health nurses agreed to participate and returned the signed consent form. I then telephoned those who had consented to participate to determine a suitable time and place for the interview to take place. During these interviews several participants suggested inviting a number of other potential participants who they believed had a special knowledge in this field. Five nurses were identified. An information/invitation sheet and consent form was then sent to these nurses. Three of these five nurses agreed to participate. This is known as the snowball sampling (Crabtree & Miller, 1999) or nominated sampling (Polit & Tatano Beck, 2006). This brought the total number of participants to 13, all of whom fitted the sample criteria.

The Sample

The sample consisted of twelve female senior nurses and one male senior nurse, ten of whom were Caucasian, one European/Māori and two Māori participants. All participants were over 40 years of age with two participants over 60. Most participants had over 16 years' experience as registered nurses, one with 11–15 years and two participants with 6–10 years' experience. There were varying education levels with three participants educated to masters' level, three to postgraduate certificate or diploma level, four to bachelor degree level and the remaining to diploma level. A demographic

survey and full participant demographics are included in the appendices (see Appendices K and L).

Data Collection

Data collection may include multiple sources in a case study (Creswell, 1998; LoBiondo-Wood & Haber, 2010). For my case study, the prime data collection methods were interviews, supplemented by some observation and documentation. All three strategies are usually involved in case study research, although rarely used equally (Merriam, 1998). One of the most important data sources is the interview (Yin, 2009). These are guided conversations allowing for iterative nature of the interview to be more fluid than rigid. Observations range from formal to casual data collections such as workplace activities, conditions of buildings workspaces, location and furnishings, however do not need to be as in-depth as some other types of research (Yin). Documentation may take many forms and for this study included policies and recommendations about the nurse's responsibilities in advance directives and their inclusion in advance care planning. However case studies do rely on multiple sources of evidence using triangulation to improve the validity and provide corroboration of the findings (Yin).

Triangulation

Triangulation is "the expansion of research methods in a single study of multiple studies to enhance diversity, enrich understanding, and accomplish specific goals" (LoBiondo-Wood & Haber, 2010, p. 119). It is especially designed to bring clarity to the findings, and minimise misperceptions and invalidities of the researcher's conclusions (Stake, 1995). Data triangulation was used in this case study

through the use of interviews, documentation and direct observation.

Individual Interviews

Merriam (1998) considers interviewing as the best technique for obtaining in-depth data in concentrated case studies. A semi-structured interview guide was chosen as a means for exploring the participants' perspectives (Holloway & Wheeler, 2010).

Interview guide

Five main interview questions were used to address the research question. The questions were designed to create an order for the interview to flow, allowing some flexibility as to when they could be asked (Bryman, 2008). I used everyday language to explain and elicit information in a way that was understandable to the participant and myself (Bryman; Merriam, 1998). Seidman (2006) suggests the main purpose of interviewing is to build on and explore the interviewee's responses to the questions. The questions included:

What do you know about advance directives?

What are your personal views about advance directives?

Have you ever been involved in advance directives?

Do you see advance directives fitting into primary health?

What do you see as the role of the primary health nurse in advance directives?

Pilot Interviews

The interview guide was piloted with two nursing colleagues who were considered experts in primary health. Piloting the questions is considered crucial to

help clarify questions and eliminate those that may return unnecessary data (Merriam, 1998). It also illustrates areas that support and detract from the objectives of the study (Seidman, 2006). I listened to the content and the ease the pilot interviewees answered the questions to ensure I was comfortable with the questions (Merriam). This also gave me some initial interviewing experience to help prepare me for the research interviews (Bryman, 2008). The questions were then reviewed, responses noted, and prompts were revised and altered prior to the beginning of the research interviews. The information obtained from the pilot interviews was not used as data for the study.

Participant Interviews

At the beginning of each interview I reviewed the consent form with each participant and gave a basic outline of the questions, the role of the researcher and the approximate time the interviews were expected to take. Setting the length of time for the interview before the process gives unity and structure to the interview by encouraging the interviewer to work within this while at the same time allowing the participant a stake in the length of time (Seidman, 2006). At this point I also asked participants to fill a demographic questionnaire (see Appendix K). I then requested the participant's permission to audiotape the interview and make notes during the process.

The questions were asked according to the interview guide. Prompts were used according to the data yielded to determine, clarify or explore relevant information. For example after the initial response to the first question about participants' knowledge about advance directives, I used several prompts to elicit more

information. Two such illustrations were “So, what form can they (advance directives) be in?” and “what about the legality of them, or validity, how they stand up?” Listening to the participant and moving the interview forward by building on what the participant shared was vital to the success of the interviews (Seidman, 2006). This is known as an iterative process (LoBiondo-Wood & Haber, 2010). Sparse notes were made during the interviews with further reflexive notes made after the interviews.

The interviews lasted between one half hour and one hour each. A small *karakia* (see Glossary p. 213) was offered at the beginning and closing of the interviews with Māori participants, out of respect for Māori protocol (personal communication, Māori Liaison Co-ordinator, 2010). At the conclusion of the interview I turned off the audiotape and recapped briefly. I then offered the participants a chance to ask questions. Conversation often continued for a short time. Seidman (2006) suggests there can be a willingness to discuss matters at this time that may have purposely been avoided in the interview. This information was not used in the analysis process for ethical reasons; however some information was gleaned from my reflexive notes, offering further insights into the phenomena.

At the conclusion of the interview a small *koha* (see Glossary p. 213) was given to each participant as a token of appreciation of their time and effort. The *koha* amount was based on discussions with other colleagues and the Māori Liaison Coordinator. A large *koha* or payment may influence participants’ motivation to take part in the study, while others argue the process could be seen as exploitation if participants are unpaid (Patai, 1987 as cited in Seidman, 2006). I asked the

participants' permission to contact them at a further date for member checking to ensure my research adequately portrayed their views. All agreed to this.

The audiotapes were then transcribed by a professional transcriptionist. A signed confidentiality form was obtained from the transcriptionist prior to this (see Appendix M). Many participants shared personal and somewhat sensitive experiences during the interview process. Sensitive issues raised in research have the ability to affect the emotional health of the transcriptionist (Dickson-Swift, James, Kippen, & Liamputtong, 2008). Therefore I checked with the transcriptionist whether the audiotapes had raised any issues for him. The transcriptionist identified no issues.

Being an Observer

Observation is a research tool considered to be a primary source of information in data collection for case study research. It may assist in understanding the context of the phenomena under study (Merriam, 1998). Interviews were held in the participant's workplace or home. Three types of observation occurred; that of the physical setting of the workplace, who was involved in the workplace and participant non-verbal cues. During the interview process I noticed the physical surrounding of the buildings, whether they had offices for privacy, how much room they had and how many worked in cubicles. I also noted how many people worked at their work settings and how this affected the utilisation of private rooms required to engage in advance directive discussions. Furthermore, I noticed posture, gestures and facial expressions indicating how comfortable the participants were discussing the topic of advance directives. These observations were jotted down after each interview.

Documentation

Documentation is considered an important source of data for case studies. They may come in many forms such as emails, letters, personal documents, written reports, proposals, reposts, studies and policies (Yin, 2009). Documentation was limited and difficult to find for this case study. Primary health providers and PHO mission statements were searched via their websites and site pamphlets but no relevancy was found. I searched the literature for relevancy to either support or refute my findings. As stated earlier, no literature specifically investigating the primary health nurse's role in advance directives was found. However some studies of other nursing specialties who provided some care in the community (Badzek, et al., 2006; Jezewski, et al., 2005; Lipson, et al., 2004; Putman-Casdorph, et al., 2009) were found and reviewed in relation to my research question. Legal Acts (Health & Disability Commissioner, 1996) pertaining to advance directives, New Zealand Nursing Council and Nurses Organisations policies (New Zealand Nurses Organisation (NZNO), 2010; Nursing Council New Zealand, 2009; Nursing Council New Zealand Te Kaunihera Tapuhi o Aotearoa, 2007) and missions statements, Ministry of Health strategies (Ministry of Health, 2001a, 2002) and documents (Ministry of Health, 2010a; Ministry of Health and Hospice New Zealand, 2010) were reviewed for relevance to the research question.

Being an Insider

Insider research involves conducting research in one's own culture or organisation (Asselin, 2003; Hewitt-Taylor, 2002). This may be both advantageous and disadvantageous. Advantages may include accessing the population, developing rapport more easily and having local knowledge of the organisation (Asselin). Participants knew I was a primary health nurse as this was stated on the

information/invitation letter. This may have helped gain entry into some organisations; I was also familiar with how many of the organisations worked.

As an insider I was able to collect in-depth and contextual data such as how primary nurses could see advance directives attached to other programmes and why they believed primary health was an appropriate setting for advance directives to be introduced. Hewitt-Taylor (2002) suggests this may be one of the benefits of insider research. On the flip side she argues some objectivity may be lost. Maintaining an awareness of this caused me to constantly try to reflect on my role as an insider. At times we joked about personal examples, such as family experiences with advance directives. This occurred because of the common bond we shared as nurses; however I needed to consciously bring things back into the researcher–participant role. I regularly stepped back to reflect on my role as a researcher. I also discussed the interview anonymously with a colleague and supervisor when confidentiality and anonymity issues or misunderstandings about questions arose. A sparse amount of subjective, sensitive information did arise in two of the interviews but this was not deemed relevant to the research by my supervisor or me – therefore the data was not used. It was especially important at this time to maintain a “mental separateness” while remaining connected to the participant (Crabtree & Miller, 1999) in order to maintain the researcher–participant role, establish credibility and provide direction for the interview.

Trustworthiness

Trustworthiness in qualitative research illustrates the methodological soundness and adequacy of the techniques used in the study (Holloway & Wheeler,

2010). Trustworthiness is established through adhering to dependability, confirmability, credibility, and transferability of the research processes and findings (Holloway & Wheeler; Lincoln & Guba, 1985).

Dependability

An audit trail is required to establish dependability (Lincoln & Guba, 1985). The audit trail includes assessing the appropriateness of the inquiry decisions and inquirer bias, and takes into account all data and the sampling designs. Dependability is enhanced by triangulation (Lincoln & Guba). Dependability in my study was enhanced by data triangulation and my research supervisor overseeing the methodological rationale and approaches used in this study.

Confirmability

Confirmability refers to the degree of neutrality or dependability of the findings. This is achieved when the findings, interpretations of the data and recommendations are logically supported by the data (Lincoln & Guba, 1985). Techniques used to enhance confirmability in my study included the use of an audit trail, data triangulation and making reflexive notes after each interview (Lincoln & Guba).

Credibility

Credibility corresponds with internal validity where results of the research are compatible with the view of the participants (Holloway & Wheeler, 2010). Techniques I employed to assist in obtaining accurate representation of the findings included data triangulation, member checking, searching for negative case analysis,

and prolonged engagement in the field (Lincoln & Guba, 1985). Member checking in my study included seeking confirmation of findings and interpretations from the study participants (Lincoln & Guba; Polit & Tatano Beck, 2004) after the analysis was completed. A letter (see Appendix N) asking participants to review the analysis of their interviews was sent to four participants. Two participants responded to this request. As a result of this process, no alterations to the data were made. A single negative case was identified during the data analysis process that did not fit the developing patterns of the findings (Holloway & Wheeler). One participant was not in favour of advance directives from her Māori perspective, which differed from the response of other Māori participants. Disparate findings from this motivated me to think about other possibilities that I had not considered during data analysis. Although I was not engaged long-term in each individual work setting during the study, I have been engaged long-term in the setting as a primary health nurse. This engagement allowed me some insight into possible misrepresentations of the phenomena.

Transferability

Transferability in the naturalist paradigm is enhanced through “thick” description of the data. It includes a detailed description of the research processes used, the context and participants in the research, inclusive of their intended meanings and the researcher’s conceptual interpretations. This allows the reader to draw similar conclusions to the researcher (Holloway & Wheeler, 2010) and evaluate whether the findings may be applied elsewhere (Lincoln & Guba, 1985). In my study, transferability was enhanced by thick description of the case study research techniques used, the participants, and my description of the researcher–participant

processes and interactions involved in the context of the case.

Reflexivity

Reflexivity involves the researcher's process of continually monitoring his or her own preconceptions about the phenomena under study, and monitoring the participant–researcher relationships in an effort to reduce researcher bias (Holloway & Wheeler, 2010). It is the constant experience of self as both enquirer and respondent (Lincoln & Guba, 2005). The researcher works with the data in choosing how it is portrayed, interpreted and analysed. Therefore, the findings are to some degree a result of the interaction between the participant and the interviewer (Holloway & Wheeler).

My experience as a primary health nurse influenced my role as a researcher, thus requiring constant self-reflection throughout the research process (Holloway & Wheeler, 2010). On the one hand, this involvement in primary health provided me with tacit knowledge of the naturalistic setting; this tacit knowledge was used to add further richness to the complexity of the data obtained. On the other hand, this tacit knowledge could have created a risk whereby I may have failed to maintain an awareness of the researcher's role and impose my own assumptions onto each of the participant's viewpoints (Holloway & Wheeler). Aware of the influences of my own experiences and beliefs in collecting and analysing the data (Asselin, 2003), I recognised the need to critically reflect on my own biases (Banister, 1999). This included biases and understandings about advance directives, my participant–researcher relationship and the reactions I experienced to participant responses. Reflective notes made after each interview assisted me to maintain this awareness and keep some distance from the participants' stories. An example of my reflective

notes included jottings on how one participant's views on advance directives in primary health were similar to my own views, in particular to when and how advance directives could be introduced. As a result of these notes, I chose to look very carefully at her transcript to try not to allow my biases override her comments.

Data Analysis

Analysing the data is an interpretive process, from the early stages of collecting data until the written report (Merriam, 1998). Data analysis involves moving backward and forwards between concrete data and abstract ideas and between description and interpretation to generate the findings of the study (Merriam).

A thematic analysis outlined by Braun and Clarke (2006) was used in this study. Abstract themes were identified by engaging in steps of analysis outlined by Braun and Clarke resulting in thick description (Braun & Clarke; Merriam, 1998). This study began with a specific question and objectives. I chose a theoretical analytical approach, using Watson's Theory of Human Caring, to code for the specific aims of the study. In addition, the data was linked to the two study propositions identified (Yin, 2009). Linking the analysis to these propositions and the aims of the study enabled me to focus on certain data and ignore other data using explanation building and cross-case synthesis. Explanation building determines causal links about "how" or "why" and may be difficult to measure (Yin). However, this was enhanced by Watson's Theory of Human Caring. Cross-case synthesis within the study involves treating each individual case study as a separate study and then aggregating the findings across the individual studies to lead to overall conclusions (Yin). To achieve this I used Braun and Clarke's steps of analysis. The

analysis was conducted both at an explicit and an interpretive level. Explicit analysis resulted in themes identified from the surface meanings of the data (Braun & Clarke). Interpretive analysis resulted in themes identified from the underlying assumptions and concepts associated with the theory I used (Braun & Clarke); that of Watson's Human Theory of Caring.

I conducted the data analysis myself, with an independent co-coder analysing four transcripts. Comparisons of the co-coding were then made with my coding to ensure there were similarities in the findings and to improve the validity of the findings (Greenhalgh & Taylor, 1997). The independent co-coder was a nursing colleague who had completed her master's research two years prior and often engaged in supporting students through their theses. After the coding process I completed the more in-depth abstract analysis and interpretation.

Due to time restraints I coded the data manually as it may have taken me several weeks to become familiar with the computer programs available to assist in coding qualitative data (Bosit, 2003). Transcripts of the data and initial coding themes were photocopied to cut and group the data according to the research question (Braun & Clarke, 2006). This gave me the ability to move the data around as I engaged in the increasingly more abstract process to eventually determine the themes. At the same time I underlined the coded parts of the original transcripts, using coloured pens. This enabled me to maintain the context while grouping for initial themes during the analysis (Bosit) and also provided an easy reference to double check the context when documenting my findings.

In an effort to provide an audit trail of the thematic analysis, Braun and Clarke's (2006) six phase framework was used to guide my data analysis. These phases are a guide only, as qualitative analysis requires some flexibility to accommodate the research questions (Braun & Clarke). These phases are summarised in Table 4.3 (p. 78).

Phase one: familiarising yourself with the data

As the principal researcher for this study, I conducted all of the interviews. As a result I had some analytical ideas and thoughts prior to the formal analysis process. I was unable to transcribe the interviews myself due to time constraints, however I listened to each interview to check the accuracy or "verbatim" account of the transcription to ensure it was true to the original meaning (Braun & Clarke, 2006). I listened once more to the data to immerse myself in the data, and read and re-read the transcripts to become familiar with all aspects of the data (Braun & Clarke). During this time I jotted a few notes of initial ideas and thoughts in the margin before I began the next phase in analysis.

Phase two: generating initial codes

Phase two began after I had become familiar with the data and generated some initial codes. I coded each transcript individually to raw semantic ideas appropriate to the aims of the study, while at the same time thinking of the latent process. This represents the "dance of interpretation" (Crabtree & Miller, 1999). I worked through the entire data set and coded as many potential themes as possible (Braun & Clarke, 2006). An example of my initial coding is illustrated in Table 4.4 (p. 81).

Table 4.3.

Phases of thematic analysis (Braun & Clarke, 2006, P. 87)

Phase	Description of the process
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collecting data relevant to each code
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic “map” of the analysis
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for themes
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating the analysis back to the research question and literature, producing a scholarly report of the analysis.

Phase three: searching for categories

After completing the initial coding, I looked across the data and collated the information into potential themes by making a list for each data set. Basic data are compressed into descriptive findings and then to the next level of analysis where themes are extracted from the data (Merriam, 1998). These categories were

developed intuitively, in relation to the purpose of the study (Merriam), the objectives and propositions (Yin, 2009), and with constant reference to my theoretical framework to develop explanations. Cross-case synthesis occurred at this stage where participants' comments were compared to each other to sort the data into units while looking for recurring themes. These units of data can be as small as one word or as large as an entire page describing an incident but must be heuristic and able to stand alone (Merriam). At this point some coding fitted into two categories. Examples of these are shown in Table 4.5 (p. 82).

Phase four: reviewing the categories and themes

This phase included two levels of review and refinement. The first level included reviewing the coded extracts to ensure they fitted initial categories. Some data was deemed irrelevant after re-reading them, while others were reworked to fit into categories, thereby creating identifiable distinctions between the categories (Braun & Clarke, 2006). The second level involved looking at the initial categories across the entire data set. Here I looked at the relevancy of the categories in relation to the data set and also to determine the accuracy with which the meanings reflected the data set as a whole (Braun & Clarke). Further coding occurred as a result of repeating this process twice. Once I was satisfied I had a reasonable idea how the categories and themes worked together that would tell the overall story, I proceeded to phase five.

Phase five: defining and naming themes

At this stage the themes were refined and defined to determine the essence of the data to be presented in the findings (Braun & Clarke, 2006). It was important

here to ensure the story of each theme could stand alone but also in relation to the other themes, in order for the overall broader story to be discussed in relation to my research question. Refinement in this stage included identifying overarching themes, sub-themes and sub-sub-themes that fitted those overarching themes. These categories should be conceptually congruent where the data is analysed at the same level (Merriam, 1998). This was reflected in my initial coding where I had four main themes; however one of these became a subset of the overall themes. I identified three main overarching themes. These were given working names, “encountering challenges”, “facilitating patient voice” and “valuing the person” and are used to present the report. A schematic illustration of the overarching themes, sub-themes, and sub-sub-themes are given in each of the findings chapters, chapters five to seven.

Phase six: producing the report

After identifying the overarching themes I was then ready to do the final analysis and write up the findings for my thesis. It was important the report be concise, logical, interesting to the reader, easy to follow and show sufficient evidence to support the identified themes (Braun & Clarke, 2006). This evidence was supported by data extracts, which were easily identifiable in the theme. Not only did these extracts support the themes generated but also supported my argument in relation to the research question and theoretical framework. Observations and documentation were then used to triangulate the data to support the themes.

Table 4.4.

Example of initial coding: What do you know about advance directives?

Data extract	Initial coding
<p><i>Not a lot. I never had any official training in it. I go into MedTech, and there'll be on the classifications, advance directive. So I'll click on it, and there's nothing there.</i></p> <p><i>Nothing in the Inbox. So my understanding is that the patient has stated how they would like to be cared for in the end time, or in the case of like a stroke or something. I say I don't know much about it: I don't know much about it in primary healthcare but I know when I had a stroke, when I was coming right, I got signed up an advance directive for myself, that if I had another stroke, and I was disabled by it, that I wasn't for resuscitation. Yeah.</i></p>	<p>1. Claims she does not know a lot</p> <p>2. Has never had any training</p> <p>3. Nothing shows up on MedTech</p> <p>4. Understands patients state care they want at end times or stroke</p> <p>5. Does not know much about it in primary care</p> <p>6. Made personal advance directive</p>

Table 4.5.

Example of Initial Categories

Initial coding	Initial categories
Thinks a will can be challenged	General understanding/unsure knowledge
Thinks a living will would be hand in hand with an advance directive	
Understands an advance directive is formal legal preference for care	Blurred knowledge
Claims she does not know a lot	Lack of knowledge
Does not know much about it in primary care	
Has had no information about it	
Not sure if living will is the same as advance directive	Unsure knowledge/legalities
Guesses it is possibility of having a legal document and leave with doctor and possibly a lawyer	
Imagines it would not be necessarily airtight	
Has seen advance directives acknowledged at tertiary level	Professional experience
Has worked with them in rest homes	
Valuable help for health and life	Positive attitudes to advance directives
Thinks they are good because you know what somebody wants	
Thinks they are a good idea – world becoming too medicalised	
Thinks we should be having those conversations but nature of 15 minutes is tricky	Positive attitudes to advance directives/complexities
Thinks they are useless as can be turned by family or in court	Complexities
How do doctors at hospitals know if there is an advance directive?	

Observation and Documentation

Naturalistic settings in primary health are often plagued with time constraints and interruptions, thus it was difficult at times to become fully immersed in the natural setting. This impacted on how much observational data was collected and may have influenced my findings. Observational data and documentation were both limited but were analysed according to the study aims and provided some support to the findings. Observational data gave me an insight into the physical settings the participants worked in, insight into the demographics of the patients that attended the clinics, the participant workload, and culture of the clinic. Facial and hand gestures, and the participant's posture often gave me non-verbal clues about their comfort in discussing advance directives. The documentation provided corroboration for the nurse's role in advance directives. Although the documentation was not specifically aimed at the primary health nurse it did provide evidence and guidance for nursing practice in relation to advance directives and support for the rationale for this study. These will be discussed in the discussion section in Chapter Eight.

Summary

Research methods used in this study were congruent with qualitative case study research underpinned by the theoretical assumptions of Watson's Theory of Human Caring. The methods were employed to determine the primary health nurse's role in advance directives and capture their complex attitudes and beliefs towards advance directives. Ethical and cultural considerations were addressed along with a description of the processes of data collection and analysis. The main data collection involved individual interviews using a semi structured interview guide. Data triangulation methods were employed to investigate the phenomena from different perspectives.

Limited documentation and observational data were reviewed and then triangulated with the interview data to provide an in-depth understanding of the phenomena of inquiry and enhance trustworthiness of the findings. Data analysis was guided by the propositions, objectives and theoretical framework using Braun and Clarke's (2006) six phase outline. The findings are described in the following three chapters.

Chapter 5: Encountering Challenges

Introduction

This chapter discusses the participants' knowledge, experience, complexities and barriers involved with advance directives. Participants were asked what they knew about advance directives, what their experiences were and whether they were involved in advance directive communication in their role as a primary health nurse. Through their responses many complexities surrounding advance directives were identified. The data was analysed and grouped together into the overarching theme of “encountering challenges”. This chapter will explain why these themes are viewed as challenges for primary health nurses in advance directives. Subthemes were identified and included knowledge inconsistencies, lack of experience, complexities and barriers. Some of these challenges could be overcome at the local level while others remain complexities until addressed at national and/or legal level. A schematic overview representing the themes and sub-themes for this chapter is presented in the appendices (see Appendix O).

Knowledge Inconsistencies

Knowledge inconsistencies were identified as the first challenge nurses may face in advance directive communication. When asked what they knew about advance directives the participants responded with varying types and amounts of knowledge. The response elicited from the first question was interesting in that four participants initially indicated they did not know a lot about advance directives.

[Int: what do you know about advance directives?]

Bronwyn: *Not a lot. I never had any training in it.*

Anita: *Not a lot, actually. What do I know? No, I'm sure . . . no, I don't actually know much about it at all.*

Jill: *Well I actually know very little.*

Denise: *Not much really, I must be honest.*

Two participants initially did not recognise the terminology “advance directives” – however one participant was familiar with the term “living will”, thus was able to expand on that. However, as the interviews progressed, for all of these participants it became apparent they had more knowledge than they first indicated, although this knowledge appeared to be unsure, blurred or made of their own assumptions.

Participants described advance directives differently. When asked what an advance directive was, one participant described what she thought it may be in the following terms and then related it to a “do not resuscitate policy” in primary health:

Libby: *I tend to think that an advance directive, rather than just being “do not resuscitate” or “no heroic actions” or . . . I tend to think of it being really wide. . . . So it might be that they go around and they put little stickers with people's names under things . . . right through to your ‘do not resuscitate’ policies . . . it's pretty broad to me, advance directives. But I think probably specifically in general practice it's a probably just a ‘do not resuscitate’ policy. Not policies but directives.*

Another participant described an advance directive as something between the patient and the doctor relating to what the patient would like to happen should they develop dementia, become seriously ill or be in a situation where they cannot make those decisions themselves. Similarly, Diane explained her views as:

Diane: . . . *My idea of them [advance directives] is that it's the possibility to state consciously ahead of time what you might like to happen to you if you're ever incapacitated and unable to make decisions around health choices and decisions, like if you're in a coma, something like that or even mentally unfit.*

Although Harriet provided a similar interpretation of an advanced directive, she was unsure how accurate her knowledge was:

Harriet: . . . *I get a bit confused about what's an advance directive and what's an advance . . . well there's all sorts of phrases aren't there so, but I'm not entirely sure what the difference is but that's my main understanding.*

In contrast, Rachel, who had recently completed a postgraduate nursing assignment on advance directives, was able to give a concrete and confident explanation of what an advance directive is emphasising the fact that a living will is an advance directive. Similarly, Bronwyn stated "It [a living will] is an advance directive, stating what they would like, or not like done."

However, it appeared most participants believed advance directives are only valid if they come in a written form:

Libby: *I think it has to be something that's actually a written up document, probably, and needs to be with somebody like a doctor, the doctor that might certify your death, or with the lawyer who might execute your will.*

Bronwyn: *I'd see it as being a legal document. I don't know whether it's signed by a lawyer. My understanding is that it would be discussed with the GP.*

Anita: *As a legal document type, I think they have to be witnessed. But people do say, verbally, to us that they don't wish x, y, z. . . . So as far as I'm aware, a*

legal document is what we would stand by. We wouldn't, I think, stand by a verbal one. Mmm.

Narelle: *I suppose they could either inform their lawyer or inform their GP. It has to be written down.*

Richard, who works in a rest home and primary health, believed that an advance directive is formalised, legalised and signed. Lesley was unsure if advance directives could be verbal.

In contrast, Rachel was confident advance directives could be oral or written. Likewise, Heather also suggested that an advance directive could be either oral or written, as depicted by her comments:

[Int: And what form can they (advance directives) be?]

Heather: *I would see it like written, and discussion with family and then enduring power of attorney type of things, mainly written, or they could talk to the doctor so it's an oral thing and he would write it down, perhaps. Yes.*

Libby, who had previously thought an advance directive must be written, later in her interview recalled being associated with Māori families where at death someone had indicated what the person had wanted. She then acknowledged advance directives may be oral but may also be ignored:

[Int: Do you know if they can be a verbal thing (an advance directive)?]

Libby: *Well I believe that they would be and do know several Māori families where at the death somebody said, "Well he spoke to me and told me to do this and that". But if the other side of the family wants to do what they do, then they claim the body as being theirs.*

The participants appeared to have their largest gap in knowledge around the legalities of advance directives. One participant was unaware there were any legalities surrounding advance directives, although she did have some knowledge about an enduring power of attorney (see Glossary p 212). Similarly inadequate knowledge was identified by the comments from Denise and Diane as they describe their knowledge about the legalities of advance directives:

[Int: What do you know about the legal aspects of it (advanced directives)?]

Denise: *Nothing. [laugh] It seems to me that the dying person always get overridden anyway, which I think is totally unfair, often by the least involved person in their care in the first place.*

Diane: *This is all just off the top of my head because I haven't had any information about it, but I could imagine that it wouldn't necessarily be legally airtight, because depending I guess on the timing around when you did it, things change as well, and health things are so complex that I can't imagine that it isn't just one of the things that would get taken into consideration if need be.*

Libby assumed anything written down in a sane state of mind must be legally binding, even if it is not witnessed. Lesley discussed how advance directives fit into the Health and Disability code:

Lesley: *The Health and Disability has the rights and responsibilities. OK? And those rights and responsibilities which nursing staff, and most probably medical staff, have to uphold, is in there: to receive treatment. . . . Then the advance directives fit perfectly within that legislation.*

As advance directives are not a well-known part of our nursing care (Wareham, et al., 2005), Rachel too was unsure of the legalities. She acknowledged advance directives

were starting to become more common but was unsure if there was any case law surrounding this.

The validity of advance directives was also unclear to many participants. The following participants' responses captured this view:

[Int: What about the validity of them (advance directives), how valid are they? What are your thoughts on that?]

Anita: *I actually don't know how valid they are . . . I actually don't know how valid they would be to be honest. No, I don't, I don't.*

Narelle: *I suppose as long as they've been witnessed by an impartial party and I suppose as nurses we could witness this, but you'd probably need a third party. I don't know. I don't know what the ramifications for that would be.*

Heather: *I don't know.*

[Int: Do you know anything about how valid they (advance directives) are?]

Pamela: *No.*

[Int: . . . you know whether they (advance directives) can be overridden?]

Pamela: *That I don't know, because the decisions then . . . if the advance directive is that she doesn't want to live, the only time, I imagine, that that's not allowed to happen . . . or when it does happen, is when the decision is actually made that she isn't for resus. And it's been made by the physicians or the surgeons, because of their condition. No.*

A further example of the confusion surrounding the validity of advance directives was identified by Libby, who thought advance directives could be overridden but she was not sure by whom.

[Int: Do you know if they can be overridden, advance directives?]

Libby: *Well I don't see why not, because your will can be overridden or taken to . . . challenged or what have you, so I don't imagine that the advance directive would be any different.*

[Int: So who do you think could override it?]

Libby: *I don't know. I guess your next of kin? I don't know.*

From her experience in elder care, Lesley related how advance directives were predominantly “do not resuscitate” orders and had to be witnessed by a nurse and signed by a doctor; she queried the validity of these. She also believed medical personnel and/or family could override advance directives and expressed the discomfort she experienced when patients wishes were overridden. Other participants were also unclear about the validity of advance directives, who could override them, as in family or medical practitioner, and whether the directives were binding or not. Rachel understood a medical professional could challenge an advance directive in court if there were any doubts about the advance directive.

Most participants appeared to be familiar with an enduring power of attorney, although some varying degrees of knowledge also became apparent. This familiarity appeared to be derived from predominantly professional experience and some personal experience. Richard interpreted an enduring power of attorney as:

Richard: *. . . A kind of advance directive. If someone feels that they're losing their intellect, they can sign over the power of attorney to a person of their choice, usually a relative or a lawyer, and that person, effectively, can then make decisions on their behalf. . . .*

Bronwyn, a stroke (see Glossary p. 213) survivor herself, had nominated her brother as her power of attorney, and therefore was able to clearly identify what an enduring

power of attorney is. Other participants associated their knowledge with having known patients enrolled in their workplace that had enduring power of attorneys. Harriet, who had worked with the Alzheimer's Society for five years, was able to describe an enduring power of attorney but was then unable to recall who it had to be signed in front of:

Harriet: *There's two parts of it [enduring power of attorney]. There's the care bit and then there's the legal protection property bit and you sign them with your power of att. . . . your attorney as in the person you want to look after your affairs when you're in a position that you can't do it anymore. And that kicks in when it is deemed you can't do it anymore. . . . So you go off and you sign those in front of someone, usually a lawyer I think. It could be anybody, I don't know, I can't remember. But they're a formal, legal thing.*

Libby, on the other hand, acknowledged she knew little about an enduring power of attorney:

Libby: *I don't know very much about the power of attorney. Not really, no. I think though that if you're maimed and you weren't able to speak for yourself and if you had appointed a power of attorney, I think they could speak for you. That's about as much as I know about it.*

The general level of education did not appear to have a significant effect on the overall knowledge of advance directives the participants had, suggesting this may not be a priority in nursing education, possibly because it is a relatively new field. Those who had conducted their own research into the topic or had worked in elder care appeared to have the most knowledge surrounding advance directives. The age of the participants may also have contributed to this. All participants were over 40 years of age with a

minimum of six to ten years' experience and most participants had been registered nurses for at least sixteen years.

Lack of Experience

A further challenge evident with primary health nurses and advance directives was the lack of or minimal experience the participants had with advance directives. All except one participant did not have any role in advance directives as a primary health nurse. Several participants who were asked if they had had any professional experience with advance directives responded with a clear no, indicated in the following responses:

Harriet: *No. No. That was an easy question*

Heather: *No. The only sort of thing that you get involved in is saying to people and referring them to a palliative care pathway but not getting down to the specifics.*

Diane: *No. I've never come across it.*

Several other participants had no experience but knew there was a section on their work computer programme to record advance directives. One participant was aware of only three or four "living wills" in the large urban practice she worked in. Other participants gave examples of personal experiences as their only experience with advance directives.

In contrast, Pamela had some minimal experience in a tertiary setting with two patients who had living wills. Neither of these patients reached a health status where the living wills were required to be acted upon and both went home. Several participants who had worked in acute settings and rest homes had some experience

with advance directives. Richard discussed his experiences of advance directives in the acute setting, relating an experience (although he was not personally involved) of a doctor overriding one:

Richard: *In the hospital situation, when I was both working in the hospital and as a tutor, I have come across the odd occasion where a patient has made it clear, in writing, what their wishes are. That is, by definition, surely must be an advance directive. . . . The case I mentioned . . . two cases I mentioned, where they didn't wish to be resuscitated. One of them was.*

He had also observed conflict when the doctor's treatment did not align with the patient's desires. From his primary health perspective Richard had observed a situation where family strife had occurred when the family had not followed the patient's wishes regarding organ donation and burial. He suggested these sorts of issues need to be sorted out. In his rest home position where his experience with advance directives was mostly positive, confusion still arose for him in differentiating between a power of attorney and a welfare guardian (see Glossary p. 214). Lesley, who had some experience with advance directives, and had previously managed a rest home, had been involved in establishing advance directives in the rest home. However the advance directives were a "do not resuscitate" policy only. This included a formal process signed by a doctor and a nurse. Lesley commented that staff initially found advance directives intimidating to work with but eventually came to see the benefits:

Lesley: *. . . I'd have to say when we first established them . . . it was really, really scary. It was really scary for registered nurses. They felt it was outside their scope of practice. And in one sense, maybe it still is, but to me it's still part*

of informed consent. . . . But as time went on I mean you could see the benefit of it as...at least you knew what to do.

In contrast to every other participant, Rachel, who had no previous experience had just recently been involved in initiating an advance directive for a patient in her current workplace. She was also in the process of developing policies for her practice nursing staff. Rachel described the situation as difficult; she noted that although some staff were very supportive, not all placed the same amount of importance on establishing an advance directive policy. Furthermore, the nurse/doctor team involved, which had an established relationship with the patient, found it very difficult to identify the right time to discuss this and waited until the patient gave them a cue before they broached the subject. Underlying this process was the belief in honouring the patient's wishes for what she wanted for her end-of-life.

Complexities

Advance directives are plagued with complexities (Munday, et al., 2007), many of which were identified by the participants. The complexities are divided into four subject headings and are discussed separately to give the reader an overall impression of how complicated advance directives really are. These four headings are: introducing advance directives, culture, communication, and clarity of advance directives.

Introducing advance directives

One of the main complexities perceived by the participants was when and how to introduce advance directives. The participants were asked about their thoughts

around the timing of introducing advance directives and whether they thought age or health status was more relevant. The range of responses and ideas around the timing of advance directives was broad, variable, often hesitant, and raised almost as many questions as answers.

Just under half of the participants believed advance directives should be introduced early. This could either be related to age or early illness. This is illustrated in Narelle's comments, who talked about the earliest time being the best time:

Narelle: Well I suppose the best time is always the earliest isn't it? I think perhaps once we start cervical screening, that starts at 20. I'm not too sure whether people would be into . . . that's up for debate, but for me, no, 20's a good start.

[Int: and when somebody's in disease or well, or where do you along the continuum do you see?]

Narelle: I suppose you'd really want to start it when they're well. When does their license start? Fourteen, fifteen? . . . Because a lot of those kids are making the choice of organ transplants and that's a huge paradigm shift, so why not then?

Rachel and Lesley added to this, suggesting illness or accidents may occur anytime in life, therefore the earlier it is approached the better:

Rachel: I certainly think it should be done earlier, rather than later. So maybe . . . I don't know. People in their twenties, maybe, through, right through. Preferably when people are well, when there is no issues. . . . You know, illness can strike people at any stage in their lives.

Lesley: . . . *fifteen, sixteen? I presume on their [drivers' license], they are allowed to consent to whether they're an organ donator or not. So if you can make that critical decision at that period of your life, then I think advance directives should come as early as possible.*

Further to this point, Lesley suggested advance directives made in rest homes were made too late, as many residents were often ready to pass on when they entered a rest home. Correspondingly, Harriet believed introducing advance directives in palliative care is too late. Alternatively, Denise thought it may be better to introduce advance directives around 50 years of age, as she had concerns about upsetting people if they were introduced at the later end-of-life when death is more inevitable. Anita, however, proposed advance directives could be made by retirement age.

The idea of introducing advanced directives in early stage illness was also suggested as an appropriate time to raise this. On the one hand, Bronwyn thought they should be introduced once people start to develop co-morbidities (see Glossary p. 212), while on the other hand she acknowledged serious illness may strike at any stage, thus indicating the complexity:

Bronwyn: . . . *but I think once you start getting co-morbidities occurring, that's probably a good time to either . . . to think about that. But sometimes people haven't got an opportunity to make an advance directive. . . . That's where you come unstuck, because if somebody is 45 and has a stroke, and they're disabled by it, I mean [the] ideal place for an advance directive to have been made prior to . . .*

This idea was supported by Pamela who thought it may be appropriate to introduce advance directive communication when co-morbidities arise or alterations in health status occur:

Pamela: . . . *so I guess it's looking at all their co-morbidities, the frequency of their admissions over a period of time, the reports back from the hospital about how their condition is . . .*

Richard supported advance directives being introduced in early disease before a person's ability to make a decision was limited. In the same way, Denise believed health status to be a more relevant factor to consider in deciding when advance directives should be introduced, but did not know when:

[Int: So what are your thoughts around the timing of introducing them (advance directives) as in age status or health status?]

Denise: *I don't know. I think it would have to be health status, it can't be age related, because age is interpretation really. Yeah, no. Definitely health status.*

[Int: As in what sort of health status?]

Denise: *Exactly. God knows. I don't know.*

In contrast, other participants felt it was more appropriate to make advance directives while a person is well, with some suggesting they could be attached to or included in other existing programmes or screening:

Richard: *Wellness. Surely that would apply to blood products and Jehovah's Witnesses . . . I think there's lots of areas where you can make an advance directive that does not necessarily imply impending illness.*

Lesley: . . . *so why is it not part and parcel of the journey of the CVD? . . . Why don't we introduce something at the end to advance directives as well? You*

know, “If this doesn’t happen” . . . whatever. So try to do that at the age of 45.

And if you’ve got family risks, you may want to bring it back sooner.

Rachel: . . . we routinely screened people between certain ages. So you could do that . . .

Denise also acknowledged it would be difficult to raise the idea, suggesting it could suit a screening situation very well:

Denise: . . . it’s a really hard thing to bring up, to do a “mini-mental” on them, ‘cos they know that . . . yeah. I struggle to do that with them sometimes, let alone. . . . So I guess it would be almost easier to do it when they’re 50, when they’re really well and healthy . . . as a screening thing . . .

In contrast, Jill felt it was complicated as people may be offended if they went to see the nurse about one thing and another issue was raised.

Culture

Multifaceted cultural views spread across personal, nursing and health cultures, and the patient’s culture, were seen by the participants as an intricate and complex part of advance directives. Many participants recognised the importance of meeting the needs of the Māori and Pacific population, acknowledging one size does not fit all and the importance of whānau (see Glossary p. 214) decision making:

Rachel: . . . we would have to think about, as health professionals, is the culture of our patients. I mean, in the Māori setting, while an advance directive is an individual choice, the culture is very much into the whānau. . . . I mean it’s not one size fits all type Māori thing, . . . I don’t know how you’d do it, and how you’d . . . sort of not advance directives for Māori and Pacific Island. . . . I’m not sure you would do it, actually.

Diane: . . . *and I can imagine that it's not necessarily something that lots of people would even want to consider, possibly particularly Māori/Pacific Island patients. . . . I think it's possibly the very gentle conversation to have around whānau support and are there things in place . . .*

Diane suggested there could be issues important to Māori beliefs around body parts and keeping the whole body together. Richard added that burial and organ donation also certainly need to be taken into account.

Pamela raised a number of complexities that she felt could arise for Māori. Her view of an advance directive was that it could be verbal but needed to be documented and suggested advance directives may be foreign to Māori:

Pamela: . . . *Māori are really not very good at doing things, in terms of paperwork. We often don't make wills. We certainly aren't very good in terms of attending, going to the hospital, and having to make a decision about resuscitation. So advance directives is something that will be foreign to Māori, especially if they're having to make that decision, or wanting to make that decision on their own, because they usually . . . always . . . have their whānau to support, or to talk with.*

From Pamela's personal Māori perspective, more importance was placed on their spiritual journey at their passing, as opposed to who makes the decision whether they live or die. She believed if it was a whānau decision it may be more acceptable but raises further questions:

[Int: So with that (advanced directives) being whānau-based, as opposed to individually-based, you wouldn't see it fitting in there?]

Pamela: *Within the whānau? Yes. Certainly. But what stage do you bring it up, and who brings it up? Does the person bring it up? Does someone knowledgeable in the family bring it up? Does the oldest son bring it up?*

She stressed that these are her own personal views and may not be that of all Māori nurses:

Pamela: . . . *So I actually don't know. I actually don't know whether it [advance directives] fits into the Māori world, no. I mean, I think it doesn't, but then in the other part of me, I . . .*

[Int: I understand what you're saying.]

Pamela: *I could be talking out of line.*

According to Libby, Pacific Island and Māori people are more comfortable with death than the New Zealand European, thus Libby believed she would not have any problem talking to them about advanced directives. Moreover, Narelle, who supported advanced directives were individually-based but also based within the family, felt comfortable in combining both aspects. When asked how she combined the individually-based concept with the family-based concept she replied:

Narelle: *Oh, gosh. It's like just in my culture sort of thing isn't it I suppose a lot of it is how people deal with death. It's accepted; it's part of life. It's not an illness. People die from illnesses but death's inevitable really, I suppose it's not really a tapu [see Glossary p. 213], but it's part of their life really, it's part of the living as well as the dead really, it intertwines, it becomes just part of the natural balance I suppose.*

Participants discussed the impact negative views about death had on a person's attitudes towards advance directives. They perceived the New Zealand European culture

as not readily able to discuss dying therefore may make advance directives for all unrealistic. Anita added she sometimes thinks patients know what is going on at end-of-life but tend not to tell the relatives. Heather, who had stated “death is somewhat a taboo subject”, explained how this may affect people’s viewpoints, while Libby suggested Māori and Pacific people are more at home with death:

Heather: . . . *it’s knowing everybody’s . . . well a lot of peoples’ attitudes towards death, they might not want to discuss it or think about it then but certainly if somebody . . . I think chronic disease it’s probably something more relevant to them. Well it depends. I don’t think it’s anything you can make a blanket ruling over.*

Libby: . . . *I wouldn’t see any barriers out here working with this population because they are mostly Māori or Pacific, and they have that whole different way of being about life and death. They’re quite at home with death. They’re quite at home with those who came before us and those who’ll come after us.*

Several participants talked about how the nursing and medical culture may struggle if an emergency situation arose with a patient who may have a “do not resuscitate” order. The assumptions and collective meanings embedded within the culture have an overall influence on the effectiveness of advance directives. Lesley explained how as an emergency trained nurse she would struggle to adhere to the directive followed by Heather’s views on how medical staff may be affected:

Lesley: *I don’t know what I would do if I was faced with an advance directive, to be honest. It’s still . . . there’s part of me says I’d turn the light off and hold their hand and say goodbye; the other part of me, because of my strong nursing, would want to battle their chest, because I’m an ED-trained nurse. So I don’t*

know. I'd most probably freak. I'd really freak if I had to, because we've been brought up to treat. Big time.

Heather: So someone would have an event, so actually go and say, "This patient has made the choice not to be . . . have active treatment. We need to stop now, and make them comfortable". Mmm. So yes, it will be interesting. Mmm. But yeah, it's that emergency situation, I think, will be the challenge . . .

Furthermore, several participants suggested the medical culture may not see advance directive communication as a nurse's role.

Communication issues

Communication issues were raised as further challenges to advance directive communication. These issues are discussed as family communication, inter and intrapersonal communication, and communication processes.

Communication within families is multifaceted, inundated with a multitude of different views and opinions. Complexities may arise from patients wanting to protect their loved ones and not wanting to involve them in their decisions:

Jill: . . . how do you spread the word from the person who's talked about it to the family 'cos the family needs to be told or needs to know and the patient may not have the courage to say whatever they want. I'm not sure . . .

Anita: . . . I think patients do, often more than relatives, understand what is going on, but tend not to perhaps make sure the rellies [relatives] do . . .

Complex cultural communication issues may also arise when some members of a family are not privy to information others have. Pamela suggested, although

helpful, verbal advance directives need to be documented to avoid family anguish and hostilities. Several participants highlighted the importance of ensuring what the patient wants is not a result of being coerced by other family members:

Anita: Yes. When they confront you together, it's a little bit difficult. You need to make sure that that is actually what the patient wants, and not being coerced by a relative. . . . Is it really the patient's wish, you know?

Lesley: . . . So that then renders that that's true and correct . . . and there's been no coercion into that person making that decision.

Communication across the health field between primary and secondary services and within the workplace was seen to be plagued with difficulties. Participants' suggested that as the general practices enlarge, they increasingly offer more services to the patient. Therefore, more and more practices are offering accident and emergency services to their patients. Anita had the experience of a patient collapsing in their general practice, who unbeknown to them at the time had a "do not resuscitate order" on their notes. This type of complexity was raised by Anita and Lesley:

Lesley: . . . and then, how is everybody going to remember who's got what in their advance directives? You know, that's a hard thing, is this, "Oh hang on a minute, I'll go to the book and just check whether they should have this and this". So it's not an easy . . .

Anita: . . . "A not for resus" Order. . . . I have come across one here, and it was for a patient we actually resuscitated. But that was . . . and then when you're presented with the emergency case, you don't actually know that.

At least half of the participants identified communication difficulties between primary health and secondary care or other providers. Fragmentation of technology resulting in inadequate communication was described as a further barrier to advance directive communication. The interface between primary and secondary care appears to be inadequate, caused by a lack of systems for the transfer of information to pass effectively between them. Some participants were able to recall situations where patients were resuscitated when they had a “do not resuscitate” directive. This emphasises the importance of structuring effective information transfer measures. Examples to support this finding are provided in the following comments:

Lesley: So certainly, if somebody at the moment in health, if they collapse and they have a “do not resuscitate” order, that’s when the advance directive comes into play. Unfortunately, sometimes somebody knows about that, but the other people that are actively providing that treatment don’t . . .

Jill: . . . and if you were admitted to an intensive care ward, how would they know unless it was tattooed on you somewhere. You can’t really take everything with you all the time, so I don’t know how people would know unless an alert was put on your hospital admitting or something. . . . I don’t know.

Harriet: . . . but also having that interface with secondary, because nine times out of ten people are whisked into hospital and they need to know what’s going on . . .

Clarity of advance directives

The clarity of advance directives was identified as a further complexity. Some participants suggested advance directives need to be very broad, in particular acknowledging one size does not fit all:

Lesley: *You know, not everybody dies from a heart attack, so why do we just have a “do not resuscitate” order, when we should be looking at other orders as well? You know the emaciated person that doesn’t want to eat again. You know, it’s that whole arena.*

Rachel: *. . . I mean it’s [advance directive communication] not one size fits all type thing.*

Clarifying ambiguous terminology and the situation advance directives may be used in were also seen as important. Furthermore, the patient may change his or her mind in different situations:

Rachel: *I think you have to be clear in which resuscitation you’re talking about. And a lot of people mean CPR. But in what circumstances, you know? . . . If you’ve got a terminal illness, and you don’t want to have CPR if you collapse or your heart stops because of that; but what happens if you get run over by a car, and you’ve got the advance directive? . . . You know, so there’s lots . . . you have to be specific about the situation, I think. Mmm.*

Richard: *For instance, again, a person may be going for heart surgery, they say, “I don’t want to be resuscitated da-da-da”. But when the time comes, . . . then they might change their mind. And they might say, “OK, well actually, under the care of the surgeon, OK. I’m talking about later on, or if I dropped in the street, or anything”. So the word “resuscitation” needs working on.*

Rachel: *. . . because they’re not able to refuse standard medical treatment, but they can only refuse non-standard medical treatment . . . the whole debate is, what is seen as standard medical treatment. Are we talking about re-hydration, are we talking about CPR? Non-standard . . . what’s non-standard? You know, so it’s all down to interpretation.*

As highlighted by the participants' responses, clarity in advance directives is imperative. Furthermore, barriers may need to be overcome to improve this clarity and appropriateness of advance directives.

Barriers

The last major challenge identified by the participants was the multitude of barriers to advance directives. These barriers fitted into three main groupings: physical barriers, process barriers, and attitudinal or belief barriers and are discussed accordingly.

Approximately half of the participants believed inadequate time would be a barrier in advance directive communication for primary health nurses:

Heather: There is the time to do it . . .

Jill: . . . *time constraints*. . .

Pamela: . . . lack of support and time . . .

Denise expanded on this, suggesting nurses would be further stretched taking on a new role, acknowledging the realities of the nurses' workloads. Other participants, however, felt timing could be overcome easily, especially with the introduction of nurse clinics:

Heather: . . . *I think they [the patients] realise that the nurses and there's more time allowed in the nurse clinic for that sort of stuff to be discussed, rather than a ten or quarter hour appointment with a doctor.*

Libby and Harriet were of the opinion conversations could be kept short by means of screening questions similar to other screening programmes already used in primary health. Most participants, however, saw advance directive communication as a

process requiring a number of visits to answer questions and clarify information:

Rachel: . . . *and maybe gave them a questionnaire, or some information on it, and get them to think about it. Go home, have that dialogue with their family, and then maybe meet – I don't know – a couple of months down the track, or something, to put something into . . .*

Harriet: . . . *a process I think that would fit in with something like Care Plus that you know you'd review it annually or whatever and you'd have perhaps the first conversation and then three months later, have another one, but if you want to talk about it in the meantime . . .*

Heather: . . . *introducing the idea of the directive and also following up in getting the person perhaps if they want to continue the discussion just getting . . . evolving this directive . . .*

The participants acknowledged that not only is general practice a service but it also runs as a business model that needs to be sustainable. Therefore, funding was seen as a potential barrier as this needs to be balanced with what the practices see as priorities. A lack of resources was also seen as a barrier for the primary health nurse in advance directive communication:

Diane: *I think there's always pressure on time anyway, and resourcing. And so it's the usual thing that the time is money and it's another conversation to be had and so it's how important it is in that list in terms of contact . . .*

Denise: . . . *that difficulty of as we know where you have public funding and private business.*

Lesley: . . . *lack of resources . . .*

In contrast, Libby and Narelle who both work in non-private Māori health providers

felt they had more time to work with advance directives and did not see timing as a barrier. Both participants emphasised the importance of making time for people but also suggested there may not be as much time pressure on them as those in privately owned general practice.

Privacy and a suitable environment were also recognised as potential barriers:

Jill: . . . *privacy, who they've got with them at the time; a lot of people bring in grandchildren, inappropriate type people who shouldn't be around.*

Diane: . . . *having appropriate time and space because it's not something you'd necessarily talk about when there are people in the other cubicles beside . . .*

Privacy can also be related to timing and funding factors. The workplaces I observed mostly had cubicles; all had side rooms but these were often shared purpose rooms. These rooms can be heavily committed; while clinical cubicles do not provide the privacy required for advance directive discussions. However, for a number of participants this was not an issue as they worked from their own designated rooms.

Personal attitudes and beliefs were recognised as possible potential barriers in advance directive discussions. A number of participants identified religious barriers and spiritual barriers while one participant also raised the idea of language barriers:

Denise: . . . *obviously personal beliefs and attitudes is a biggie.*

Narelle: *Perhaps language barriers for some. There would have to be religious barriers for some people, spirituality barriers, perhaps people are not comfortable in that spirituality, whether they believe in it or not.*

It is not only the beliefs of the nurses that were seen as potential barriers but also the doctors and the patients themselves:

Denise: *And the patients, how they would react to seeing stuff like that. They might find that offensive might think, oh we're trying to kill them off.*

Heather: *. . . where I guess doctors would be ideal to deal with it but they have the same perhaps the same reticence or reluctance to talk about death and dying.*

The nurse's own discomfort in discussing death and dying may also be a potential barrier for advance directive communication:

Narelle: *Maybe some people have a . . . perhaps they don't want to go into that place for some nurses . . .*

Anita: *. . . it probably comes down to a person's beliefs, really. Some people are more comfortable doing things than others.*

A lack of cohesion amongst the staff was identified as a potential barrier to implementing advance directive communication:

Anita: *So yeah, I think the barriers are probably staff buy-in, to make sure everyone's on the same page . . .*

Richard: *I think one of the biggest barriers would be getting the medical staff on board.*

This lack of cohesion can occur as a result of differing personal beliefs or attitudes and also the reluctance or discomfort in discussing death and dying. Several participants also believed some medical staff will not see advance directive communication as a nurse's role.

Nurses with strong opinions about advance directives may also build barriers, as discussed by Bronwyn, who emphasises the importance of being impartial:

Bronwyn: . . . *If you had a nurse who had very strong views about something, I think that would be a hindrance too. It's got to be impartial.*

Harriet: . . . *I guess people might have strong opinions on you know . . . that will stop certain people having those conversations.*

Finally, Narelle raised a poignant but significant point about introducing advance directives suggesting there may be other more pressing health issues that they work with:

[Int: . . . I'm looking at those sorts of barriers as well, I just want to see if you can think of any?]

Narelle: *I don't know. I'm just thinking of the complex cases that I deal with: poverty, cold homes, oh and while I'm at it . . .*

As illustrated, the participants have identified a number of potential barriers that need to be overcome for advance directives to become a routine part of their primary health nursing role. These barriers were identified in the physical setting, in the fragmentation of technology and differences in the attitudes and beliefs of the individual.

Summary

This chapter discussed the theme “encountering challenges,” a finding that was derived from the comments of the participants in this study. Four main subthemes were identified that fit into this theme: knowledge inconsistencies, lack of experience, complexities, and barriers.

Despite advance directives being a health term in New Zealand since at least

1996, several participants were not familiar with the term. However most participants had a general knowledge about what an advance directive was, despite offering varied descriptions as to what they may be. Further to this, a lack of sound knowledge on the legalities and validity of advance directives was acknowledged by most participants.

There was very limited or no experience with advance directives in general by most of the participants. Only one participant acknowledged she had a role in advance directives in primary care. This had occurred just two months prior to the research interviews; this had been her first advance directives experience. Two participants acknowledged they had some experience with advance directives in rest homes. Two other participants recalled professional experience with advance directives in hospital settings; however, these two participants did not have a direct role with the patients in those advance directives processes.

A number of complexities were identified creating further challenges to the primary health nurse's role in advance directives. Intricacies around when and how to introduce advance directives were identified by nearly all of the participants. Other complexities included the influence cultural and personal attitudes have on the appropriateness of advance directives. Participants identified disparities between Māori and the Western culture in attitudes towards death and dying. These attitudes towards death and dying affect the nurse's ability to initiate advance directive discussions. Complex family and personal communication dynamics were also highlighted as complexities. Furthermore, the clarity of advance directives were questioned, with participants recognising that one size does not fit all.

Finally a multitude of barriers were identified by the participants. A lack of time for already stretched health professionals was identified as a barrier by most participants. Inter and intrapersonal communication issues that face health professionals were raised as barriers, in particular fragmented communication across the health sector. Further barriers included privacy factors, funding issues, personal beliefs and attitudes towards death and advance directives, lack of staff cohesion and potential language barriers.

Although these challenges raise many questions and complexities to be addressed, these were overridden by a belief that advance directives facilitate patient voice and the fact that advance directives should sit in primary health. The following chapter is dedicated to discovering why the participants believed there is a role for the primary health nurse in advance directive communication and outlines ways in which this could be achieved.

Chapter 6: Facilitating Patient Voice

Introduction

This chapter describes the participants' views surrounding advance directives and the role of the primary health nurse in advance directive communication. Having determined in the previous chapter that 12 of the 13 participants are not involved in advance directive communication in primary health, this chapter discovers why the participants believed there is a role for them to play. The findings related to "facilitating patient voice" in this chapter are presented as: attitudes, influences, relationships, and role of the nurse. Figure 6.1 represents a schematic summary of the themes and sub-themes for this chapter (see Appendix P).

Positive attitudes to Advance Directives

A positive attitude to advance directives was one of the predominant sub-themes that emerged from the analysis. There were many diverse reasons as to why the participants favoured advanced directives. When asked their personal view points about advance directives there was little hesitation in declaring a favourable response to them. Examples of participants' responses are:

Harriet: Well I think they're absolutely . . . very, very useful and very good, because they're what people can do, you know you can make your decision when it's not a crisis. And you can say 'OK I don't want to . . . '

Jill: I think they're a good idea. I think the world is becoming too medicalised. People should be allowed to die when it suits them and not when some doctor says they should.

Narelle, who favoured advance directives, believed that current changes in health attitudes and medical advances indicated advance directives are needed even more so at this time.

In contrast, Pamela, a Māori participant, was not so positive about advance directives. Although she could identify positive features about advance directives she believed they fitted more into the Pākehā (see Glossary p. 213) world and was unsure whether she believed in them for Māori or herself. This concept was demonstrated in her comments:

[Int: What are your personal views about advance directives?]

Pamela: *I guess it's a Māori . . . it's a Pākehā philosophy, it's not Māori.*

[Int: So you personally don't see them [advance directives] as being something that you would believe in?

Pamela: *Ah. Believing is different to using. [Sigh.] Probably not. Probably not. . . And I can't speak for other Māori, in terms . . . but I do know our family, and my husband's family, what we would do, where we would go. Rather than . . . It's more to do with where we'd go, rather than who makes that decision, whether we live or die.*

Pamela acknowledged that advance directives may fit with Māori culture if they are whānau-based as opposed to individually-based. She then went on to raise the question about what stage advance directives should be brought up and who would bring the topic up with the whānau.

Values, beliefs and experiences were key factors in determining the nurses' attitudes towards advance directives. These included personal and/or professional

experiences, personal and nursing cultural values, and religious and family influences. Each of these factors are discussed in the following paragraphs.

Personal experiential influences

Personal experiences with the death of a family member or friend were recounted by eight participants as having influenced their views on advance directives. Some participants recounted positive experiences with a family member or friend dying a peaceful death who had previously stated what their wishes were at end-of-life. While other participants described more negative experiences where they believed the dying patient received futile treatment that would not have been congruent with the patient's beliefs. The participants believed advance directives may have helped those patients come to a peaceful death. Therefore, both positive and negative experiences validated the participants' positive beliefs about advance directives. Heather's comments illustrate how a positive personal experience influenced her views:

Heather: *Probably my father died from Myelodysplasia, and the end of his life occurred when he . . . he'd had a massive . . . but before that he'd said to us there's to be no heroics so when the time comes for him to die . . . well yes. So there was nothing written down but he'd made his wishes known to us. On the day that he died he was competent enough, thank goodness, to say no . . . they offered him treatment in intensive care you know. And he said no. And that was fine so then they began giving him enough pain relief, sort of palliative care and he died later that day.*

[Int: So that worked quite well for him?]

Heather: *Yes it did.*

[Int: Yeah. And for the family?]

Heather: *Yes, we 'd already discussed what he 'd . . . it wasn 't a big formal discussion it was just this is what was going to happen and my mother and him had also discussed it.*

However, Rachel encountered two complex deaths in her family, which influenced her views:

Rachel: *And you often think – and I've had that happen twice, actually, personally. I've had two family members die, where both of them, I felt, weren't comfortable. There were procedures done where I'm jolly sure if they could have spoken for themselves, they wouldn't have wanted it . . . and as I say, having had personal experience of family members not having the ability to have an advance directive, where it would have worked quite well for them. Mmm.*

Nurses need to be equipped through their education and their experience to be able to hold these sensitive end-of-life conversations. By accepting aging and death as a normal part of life, and by using reflection, nurses may increase their capacity to care for people (McNeill, Shattell, Rossen, & Bartlett, 2008) and their ability to hold these types of conversations.

Family beliefs were also identified by several participants as triggering positive attitudes to advance directives. Libby remembered many conversations with her parents about dying or not dying and remaining in the world with no way of communicating. This influenced her thinking from the outset. Her father never wanted to “be a cabbage” (colloquial term for a person in a coma or totally incapacitated) and her mother who suffered from chronic obstructive airways disease discussed how and when they would discontinue any interventions.

Professional experiential influences

Similar to personal experiences, a majority of participants identified professional experiences where patient deaths had influenced their thinking on advance directives. These also were in the form of either positive or negative experiences, with several participants identifying the importance of quality in dying. Most participants referred to negative experiences they encountered, associated with difficult deaths:

[Int: What's brought your views about? What has influenced your views?]

Lesley: *Oh, I think because I've dealt with so much death and dying that quality of dying, to me, is the most important thing you can give a person. And I believe that if a person has a choice, and they don't want to be treated, and they've made that decision very clearly, then actively going against their wishes, to me, doesn't help a nice death.*

Richard: *. . . first of all, in my nursing practice, particularly in the 70s, 80s I have seen too many people resuscitated that shouldn't have been.*

Anita: *I suppose, partly seeing people kept alive for the sake of being kept alive, with no quality of life.*

A number of the participants believed the length of time and/or type of work had influenced their views:

Harriet: *I guess like 150 years of nursing . . .*

Narelle: *. . . my experiences . . . I did work in a rest home and for me a rest home is quite a waiting room. That's their last end stage practically.*

Harriet further discussed her wide experiences dealing with the dying had caused her to think about the nature of death. Over the years she had seen unpleasant deaths where some interventions seemed futile to her, so she viewed the dying process and how it is experienced by the patient as more important than keeping someone alive:

Harriet: . . . *probably 80% of my clinical time was with terminally ill people and lots of people with HIV . . . so who were all dying and had usually looked after a partner who had died in quite a nasty way. So I guess I've thought about the nature of death quite a lot in my professional life mostly. . . . Is it that we should have more of a choice over the way it is, in not so much the timing but in the actual how you die? You shouldn't have to go through certain things . . .*

Pamela acknowledged her past acute nursing experience and involvement in whānau contributed to her attitudes towards advance directives. However, she identified the strong emphasis for her was the need for the whānau to be well-informed, not through just passing information on to them, but ensuring they understood what was being said. Nurses are in a pivotal position to recognise patient and family vulnerability (Pavlish, Brown-Saltzman, Hersh, Shirk, & Nudelman, 2011) and have as core values ethics of caring to act as advocates and communicate patient needs to others (New Zealand Nurses Organisation, 1997).

Pamela: . . . *and also being a nurse, and being . . . working in acute areas, has made me more aware of how I can support families. Particularly whānau. And yeah, and I've got a really strong sense that they really need to be well-informed. And it's not just informing them, but making sure they understand what you're saying.*

Denise talked about her experience in Oncology, medical wards, emergency departments and particularly general practice where she had seen strong, independent people become just shadows of their former selves due to the aging process or disease. She explained their rights were “just whipped away” and felt these patients may have benefitted from well-prepared discussions. In contrast, Heather had known of patients

who had stipulated they did not wish further treatment at end-of-life resulting in a peaceful death. These directives were made at the terminal phase of their lives and influenced Heather's positive attitude on how she viewed advance directives.

Cultural and religious influences

Cultural and religious influences played an important role in contributing to the participants' attitudes about advance directives. The culture of health has changed over the years. Mechanical advancements such as respirators and life prolonging medical treatment have given rise to a more technical focus in patient care at end-of-life (Brown, 2003). Many of the participants indicated this technical focus in patient care had escalated to a point where patient rights were ignored as the health system appeared to focus on maximum life preservation:

Harriet: . . . *I think there's much too much heroics going on in medicine and healthcare for people who are older or sick. I mean that's fine if they want them, but I think there's much too much . . .*

Jill: *I think being part of the health system, seeing how it's changed over the years. Everything becomes very technical when you're a patient. I just sort of think things have changed and you're not allowed to . . . they've put all this money into keeping people alive or fixing things that are broken that could have helped, you know . . .*

A number of participants identified with Christian beliefs while other participants identified personal beliefs originating from the Steiner philosophy (see Glossary p. 213), atheism or pragmatism. Although these personal beliefs contributed to the participants' attitudes towards advance directives it was ultimately their

commitment to principles of holistic patient care, respecting patient rights and patient choice that were foremost in their attitudes toward advance directives. These principles are embedded in the culture of nursing. The nursing culture includes a combination of mission statements, policies, procedures, language, beliefs, unwritten rules and customs (Anthony, 2010), meanings, roles and rituals that differentiate nurses from other healthcare cultures (Street, 1995). Often aspects of nursing culture are taken for granted and become “invisible” to nurses (Street) but underpin nurses values and attitudes. Bronwyn’s comments emphasised how the foundation of her nursing values took priority over her approach to her patients:

Bronwyn: . . . *being a Christian, I do have strong beliefs about certain things, but I can’t let that influence patients I’m looking after. Part of my pledge as a registered nurse is to treat them as an individual, and not be biased towards anything.*

Lesley discussed how her values as a nurse were paramount in her actions and attitudes towards her patients in term of advance directives. These values overruled any conflicting religious beliefs she may have had in relation to advance directives:

Lesley: . . . *it’s most probably against my values and beliefs, because I’m quite . . . because my religion is Catholic, and of course I have some very strong views on life and living, and things like that. But I think from my nursing experience, and the wisdom that I’ve gained from my nursing experience I still believe there’s a necessity for them in health.*

Many participants raised the idea of euthanasia (see Glossary p. 212) when asked about what influences their views; most reported that they did not support this concept. However in contrast, one participant who raised this idea was strongly in

favour of euthanasia while another participant was unsure whether she supported euthanasia or not. The idea of euthanasia was raised by many of the participants; however, this was not a focus of this study so no further investigation of the topic was undertaken.

Māori culture was an important influence for three participants in their attitudes to advance directives. Narelle believed her Māori culture was part of what framed her construct. Her ethnicity, background and views influenced her positive attitude towards advance directives. She believed the way Māori viewed death as a natural part of life was an important factor in how she viewed advance directives:

Narelle: . . . *Oh, gosh. It's like just in my culture sort of thing isn't it. I suppose a lot of it is how people deal with death. It's accepted; it's part of life. It's not an illness. People die from illnesses but death's inevitable really, I suppose it's [inaudible phrase] it's not really a tapu, but it's part of their life really, it's part of the living as well as the dead really, it intertwines, it becomes just part of the natural balance I suppose. . . . I suppose from my own construct, it's my view of the world, my ethnicity, my background, just who I am . . .*

Māori are quite comfortable with the notion of death (Clair, 2005). Health, healing, illness, death and grieving are a central part of Māori life, maintaining unity and balance and allowing the person to live in harmony with the natural, physical and spiritual world (Ngata, 2005). The laws of tapu (see Glossary p. 213) in contrast to noa (see Glossary p. 213), rituals and customary practice are what preserve this balance. Each person contributes to the health and wellbeing of their whānau, thus when there is loss through illness or death, the family network is weakened, with the most vulnerable members given special care and support (Ngata). Correspondingly,

Denise believed that her Māori background also influenced her view and that the concept of advance directives was tied up with the care and value of the family and whānau. The following example indicates her viewpoint:

Denise: As a Māori grad too obviously there's not specific a Māori thing about it but there is that care whilst the person is still alive, but that is all intertwined with the whānau and spiritual and the value of a person until they're gone.

Pamela identified three major influences: her health knowledge, her life experiences and her whānau, much of which is based in tikanga (see Glossary p. 213) Māori. She had been nursing for over 40 years and had lived in a "Pākehā" world until more recently when her life circumstances changed and she moved more into the Māori way of life. Each of these influences contributed to her overall attitude, with each influence as important as the other. Pamela acknowledged that differences in the way Māori, Pākehā and health professionals viewed death contributed to some internal conflict:

[Int: So your Māori culture influences you most? Do you think?]

Pamela: . . . No. I have to say, the influences come from the whole. I can't say one is stronger than the other, but I can't say I can't be without each . . .

Int: . . . And so I can see that it can come into conflict with you?]

Pamela: Oh, very much so.

Diane also identified the different perspectives we bring to every situation in our professional and patient relationships, cautioning that we need to have an awareness of this:

Diane: . . . *I also understand that I bring my perspective to it, actually as a human being, and I think that's where we need to take care around things like this, because actually we all come from very different perspectives.*

Overall, culture has an important role in how we construct our ideas to form our viewpoints (Anthony, 2010). As indicated by two participants, these influences are inter-connected and put together, make up the whole of the person, creating many different points of view. These influences created positive attitudes towards advance directives for most of these participants.

Positive Attitudes to Advance Directives

Participants not only revealed favourable attitudes towards advance directives in general, but it became evident this also applied to advance directives in primary health. So as not to presuppose that advance directives fit into primary health, I asked a closed ended question that was to be followed up with a prompt. However, the question was answered emphatically by most of the participants and clarified with little or no prompting required. The question was: "Do you see advance directives fitting into primary health?" All participants believed advance directives sit in primary health. The positive responses were qualified by the participants as to why they believed that advance directives were appropriate in the primary health setting. Bronwyn's comments illustrate the positive response to the question and her reasons why:

Bronwyn: *Oh, absolutely. Because people are being managed in primary health, whereas 20 years ago they were managed in hospital, you know, if they were unwell. But people are managed in their own homes. And a lot more people are wanting to be managed in their own homes, in their own familiar surroundings. So definitely in primary health.*

Anita further supported this concept, indicating she believed that advance directives should sit in primary health as more health services are being moved into primary care. This is particularly relevant to the “baby boom” (see Glossary p. 211) population moving into the next age bracket. Although Pamela believed advance directives should sit in primary health, she qualified her viewpoint by commenting she could see them fit there predominantly for non-Māori. Diane believes the primary health practice is the home base and described the holistic aspect of advance directives in primary health:

Diane: Well I think for me, I so support that the primary health practice is the home base, and I see it definitely has the role in terms of understanding the connections between health and social well-being and consideration of those sorts of things, the preparedness. It's holistic actually.

The prevalence of patients suffering chronic debilitating disease that often requires early decisions was another factor supporting the belief that advance directives should sit in primary health. This was indicated by Richard:

Richard: Yeah. I do. There's whole areas of primary health where people have to make decisions fairly early. Chronic debilitating diseases, such as motor neurone disease: how long . . . I mean, you can keep someone's motor neurone disease going for ever, just about. How . . . or what stage do we decide . . . so that's an ideal one for advance directive.

Primary health was seen to be a key element to developing advance directives. Several participants commented on the purpose of primary health – to promote health and wellness in the community with people taking more responsibility for their own

health. Participants believed they were in an appropriate position to engage in advance directive discussions due to the long-term relationships they had with their patients.

Long-term relationships

Continuity of care, good relationships, long-term and trusting relationships were all described as key factors to why advance directives should sit in primary health. Denise suggested nurses who hold a familiar and often intimate relationship with the patient may notice them getting older or frailer. Harriet suggested teams of doctors and nurses who have the long-term relationships with the patient could begin having advance directive conversations as they are much harder to forge in secondary care. Many participants identified relational longevity as important to advance directive communication:

[Int: . . . why do you think it's (primary health) an appropriate place?].

Denise: *Very, very appropriate. I think that's where it should be, particularly because I do think relationships are grown better with the enrolled . . . with the PHOs and stuff like that, that we are developing better relationships, that people are, well I think they are.*

[Int: So why do you think it's an appropriate place?]

Denise: *Because we have that continuity with patients . . .*

Diane: *Because I think in primary health we try to evolve the long-term trusting relationship around health and issues that impact on health and things that can be considered around it. Yeah.*

Long-term trusting relationships in primary health where the practitioners know the person and their values and circumstances were believed to be important in advance

directives. These relationships are considered integral to the role of the primary health nurse and primary care team (Hsu, Phillips, Sherman, Hawkes, & Cherkin, 2008).

The Role

As discussed in Chapter Five, it was acknowledged that only one participant engaged in any role in advance directives in her practice as a primary health nurse. Rachel, who worked in a large practice, relayed her singular experience with an advance directive only several weeks prior to her interview for this study. It was a new arena for her and her workplace. The complexities involved in establishing the advance directive were worked through in a fashion that was ethical and suitable to the patient and the practice team. At the same time they were looking at developing a policy for the practice around this.

Although no other participants played any direct role in advance directives, all believed primary health nurses had the potential to become involved in a role in advance directive discussions. Multiple ideas were introduced on ways and means nurses may introduce advance directives in primary health. These included teamwork, initiating and recognising cues, raising public awareness, keeping it simple and suggestions as to what the participants' believed was required to expand into this the role.

Teamwork

All participants believed teamwork was instrumental to successful implementation of any role the primary health nurse could have in advance directives. The culture of nursing practice, the willingness of the entire practice team, particularly

the doctors to embrace the concept, team decisions and role delineation were seen as important factors in the process. An example is shared by Richard and Heather:

Richard: . . . *You would have to have willingness of the medical practice to, as a whole, to embrace it. You couldn't have . . . I don't think it would work if you had a situation where one particular doctor objected, but all the others did.*

Heather: . . . *You'd really have to talk up on the conversations to the GPs about it, for them for everybody to be comfortable about who's doing what.*

Furthermore, Diane suggested early practice team discussions would be required to develop a mandate around the importance of advance directives. This would develop a good understanding into what it means for the team. This may indicate who would be comfortable discussing advance directives and enhance the workforce development of the team. Teamwork was identified as important throughout the process especially in creating guidance and delineation of each practice team member's role in advance directives.

Potential primary health nurses' roles were discussed to determine how the participants envisaged a role in advance directives. One participant suggested regularly checking with the doctors as to when the timing may be appropriate to introduce advance directives to the patient. Participants believed this communication may recognise patient cues and would provide a base for the team to work in collaboration in an effort to provide patient-centred care.

Initiating and recognising cues

Initiating conversations, looking for cues that may indicate the patient is at a stage they may be willing to discuss advance directives, ensuring adequate information

was given and acting as an advocate for the patient were seen as important factors in advance directives. More than half of the participants believed it was appropriate for the nurse to become involved in early discussions or initiate early conversations about advance directives to provide initial information to the patient:

Richard: . . . *but I think we'd need to be the initiators . . .*

Bronwyn: . . . *I see it as we're more involved in the initiation of getting an advance directive established . . .*

Anita: *As in, I think, they need the information first, they probably need to go away and discuss it with families and family members. It's not a decision you can make there and then. . . . It's something that you do need to think about, and go away and discuss with partners and relatives, and then come back and discuss with their doctor. Mmm. And maybe even then, it's go away and think again, and come back . . .*

In contrast, Pamela believed that nurses should only play a role in advance directives if asked to. This is reflected in her response to my question:

[Int: . . . What do you see as the role of the primary health nurse in this? (In advance directive communication?)]

Pamela: *I think being honest, when she's asked. And if you've been asked, and start looking, to understand what it means.*

Almost all of the participants believe the formalisation of the advance directive needs to be completed by the doctor:

Anita: . . . *and then come back and discuss it with their doctor . . .*

Heather: . . . *the nurse would be able to introduce more . . . spend more time introducing the idea and then broadening out . . . to follow it up with the doctor, if you like, the formalising of it.*

Others suggested nurses may need to notice when advance directives could be appropriate and then initiate conversations about an advance directive. Richard acknowledged the important role nurses have in initiating these conversations and then ensuring the patients are equipped to be able to establish an advance directive:

Bronwyn: . . . *so listening for those clues, and getting something established.*

Richard: *I think we'd have to be . . . [laugh] I think we'd have . . . I hate to say this, because we've got enough to do, but I think we'd have to be the initiators, and we'd have to notice when it's needed. Yes. And pull the threads together.*

Aligning with these proposals, Lesley believed that the nurse is in a prime position to work in collaboration with the patient's doctor to establish patient-centred advance directives. The nurse's role would be to ensure the patient is confident in the informed decision making process. For this to occur, adequate information would be required; at the same time ensuring all steps had been documented in the patient's notes. One participant suggested the nurse plays a supporting role to the doctor who often does not have time to give the patient all of the information. Yet another described how nurses have the ability to empower patients by ensuring adequate knowledge and information is given to the patient about advance directives.

Patient advocacy is a core component of the registered nursing role. This has become increasingly important over the last 30 years. According to Bu and Jezewski (2006) there are three core features to the advocacy role. These include safeguarding patients' autonomy, acting on behalf of the patient and ensuring social justice prevails in healthcare (Bu & Jezewski). Patient advocacy was identified as key component in advance directives by a number of participants. Rachel talked about sitting alongside,

supporting and advocating for the patient throughout the process of establishing advance directives:

Denise: . . . *I think that again that advocacy thing for the patient comes up.*

Rachel: *I think the role of the primary health nurse is to support the patient in their wishes, is to act as an advocate for the patient, and to ensure that the patient has thought about all the realms . . . and I think too, the nurse, their role is to support that patient while they're writing . . . and that the nurse, you know, is their advocate, but also sitting there alongside them, and ensuring that their wishes are written down correctly.*

A number of participants believed that the nurse had the potential to develop unique relationships that were different from doctor–patient relationships, identifying sometimes the nurse may be seen as more approachable. Narelle spoke of valuing the nurse's unique position in relation to families and choices, thus accentuating the strategic role nurses have in discussing advance directives with the patient and their families. Diane suggested that not only the shorter consultation time the doctor has with the patient, but also the level of conversation held between the doctor and patient is often conducted at differing levels from the nurse-patient consultation. Diane then explained why she believed the nurse has more scope to conduct advance directive discussions:

Diane: . . . *So I could see that it's actually a conversation that the primary health nurse would do quite well. Because it would need the information into the process and actually the care that you're hearing how it needs . . . that you've picked up how it needs to be spoken. So it could be heard how you wanted it*

received, rather than having a reaction against it because it wasn't spoken in the right way, and I think we have more scope to do that.

Several participants identified the need to raise public awareness around advance directives and believed that this fits the role of the primary health nurse. Diane and Libby contended:

Diane: I think it is just about raising awareness . . .

Libby: . . . I mean certainly when the first time you're talking about that with people, you're just raising awareness . . .

Raising public awareness

Long recognised as an integral part of nursing, health awareness and health promotion appear to be important factors to the potential implementation of an advance directive programme. A number of participants raised the importance of having supporting literature or advertising available to the patient in the form of pamphlets to read or posters on the surgery wall:

Denise: . . . have the information around the practice so that people can see it . . . and then it is an alright thing to discuss.

Jill: I suppose you could have a poster up in the waiting room saying "talk to your doctor about this if you are interested" . . .

One participant who supported this idea recommended that rather than abruptly raise the topic of advance directives with patients in primary health, the community may need to be primed a little first with some low key publicity. Harriet pointed out that one Australian state gave out pamphlets on advance directives in cafés in an effort to normalise them; she wondered if that idea would work in New Zealand. Further to

the need of raising public awareness the participants recognised the need to keep the process simple in initiating advance directive discussions.

Keeping it simple

Easy processes to establishing advance directive discussions were considered important by many of the participants for successful implementation. This is illustrated in the following comments:

[Int: What would be the most important thing about them (advance directives) that you see?]

Harriet: *I think everyone understanding what they're for, making it an easy process like an advance form or something . . . because if they are not quick and easy they are not going to get done are they?*

Libby: *I'm sure that some nurses would say: "Oh we haven't got time to be doing all these things". But that's what they said when they brought the family violence question in, and over time, people get used to asking those things, and they start putting them into their practice. I don't think everything that's a new idea has to be a big bloody trek down the . . .*

When asked how advance directives could work in primary health, several participants suggested it could be introduced in a screening process. Denise believed that screening was a good option; she believed that advance directive communication would not occur opportunistically. Heather spoke of the need for structured processes in terms of initiating advance directives. She understood advance directives could be a difficult topic to raise but suggested a way this could be initiated:

Denise: *Probably as a screening situation . . .*

Rachel: . . . *bit like we started the family violence programme at our centre.*

And so we screened . . . we routinely screened people between certain ages. So you could do that.

Heather: *It's like doing a checklist of all the things that you talk with somebody about. And it's one of those things that you introduce as a topic I guess, it's 'have you thought about' you know? Or yeah but it would be a very difficult topic to talk about I'm sure [laugh] And maybe not until you . . . yeah. It wouldn't be for the faint-hearted to because I don't think even the doctors approach that topic successfully.*

Approximately half of the participants believed that advance directives could be raised with some other type of existing programmes, such as the palliative care pathway care plus, cardiovascular disease clinics, get checked diabetes clinic or the newly trialled chronic disease management clinics (see Glossary, p. 211–213 regarding these programs). In contrast, Jill did not see the topic of advance directives alongside other programmes such as the diabetes or cardiovascular risk clinics.

A number of participants suggested that using an advanced form (see Glossary p. 211) to establish advance directives could keep the process simple. One participant suggested an alert could be placed on the patient's file, indicating the idea of advance directives had been raised or an existing advance directive was held.

Participants believed that the formulation of advance directives was an evolving process that would need to be built upon. They suggested this could occur by initially raising the idea and then allowing time for the patient to reflect on what it may mean for

them. This would also give the patient time to discuss the topic of advance directives with family members; thus allowing time for the patient and their family to ask any questions. This is clearly illustrated by Libby's comments:

Libby: Well it's something that I believe that you would build on. And the next time you see them you might build on it a little more. Next time you see them, you might ask for some feedback. Have they been thinking about it? Are they feeling like they're at a place where they want to write anything down. . . . Have they had a discussion with people that they care about around them?

Harriet: . . . a process I think that would fit in with something like Care Plus that you know you'd review it annually or whatever and you'd have perhaps the first conversation and then three months later, have another one, but if you want to talk about it in the meantime then usually they're back before three months anyway let's have some sort of flag to say we've got this on-going, how're you feeling about that?

Overall, the participants' comments illustrated the altruistic characteristics of kindness, concern and empowerment for their patients. These characteristics are inherent to the culture of nursing and were particularly relevant to the primary health nurse's role in advance directives.

Support for Nurses

It appears there is much groundwork to be accomplished to enable primary health nurses to work with advance directives. All of the participants acknowledged a need for education about advance directives. Many participants recognised the need for more knowledge about advance directives particularly in relation to the legalities

surrounding them. These needs are illustrated below in Heather's comments about education and Richard's recommendations about the legalities of advance directives:

Heather: *Well, the education side of it. You need to know exactly what is involved, what it is, and all the ins and outs of an advance directive.*

Richard: *They would need . . . well, they would need to know the process thoroughly. So whatever the legal process, whatever the . . . because it might vary from practice to practice a little bit anyway. But whatever the local processes and the legal processes are, the nurse would need to know them. So you'd have to have effective preparation of the nurse.*

Some of the participants believed that it would be important to have clear guidelines around the role:

Anita: *. . . Clear guidelines, I guess, we need clear guidelines . . .*

Heather: *. . . you need to know exactly what is involved, what it is, and all the ins and outs of an advance directive . . . the legalities of it, how does it apply, who can override it . . .*

Several participants described the need for a resource person who has a specialty in advance directives and who can deal with complex questions as they arise:

Denise: *. . . A go-to person, somebody who has a specialty in that, like a nurse practitioner of that area or a contact person that you can speak to . . .*

Rachel: *. . . And maybe she would need some sort of peer support, because a lot of those questions might be quite difficult.*

Correspondingly, two participants also acknowledged the need for support from within the practice and also the Primary Health Organisation. Another participant stressed the need for early and regular follow up and review of the advance directives. In this way nurses would feel supported, secure and confident in their role with advance directives.

Resources and effective leadership were identified as important in enabling the primary health nurse to work effectively in an advance directive role. For example, some participants identified that the nurse may require education on how to communicate in advanced directive situations. The complexity is illustrated below with Jill's comments. She described the need for nurses to learn about advance directives as part of their role but suggested that families and their doctors may make the final decisions:

Jill: This nurse might need some training on how to broach the subject, how to document it, how to talk to families about it and how to, once a person's made a decision that they don't want to be kept alive for ever, how do they help them tell their families, if that's what they're wanting. But I do believe that when the crunch time comes, the doctors and families will have the final say.

Lesley raised an important idea should advance directive programmes be introduced as part of the primary health nurse's role; the programme should be research-based with a cohort group. The programme would also need to be closely monitored and evaluated prior to general implementation. She believed that because advance directives are a new arena for nurses it may need to be built into the nurse's scope of practice. Lesley argued that staff required for the job must have a special interest in and be willing and competent to take on a role in advance directives. A further participant added to this idea and suggested it would be helpful if the nurse had an interest in palliative care. Most participants acknowledged that nurses need to be good listeners in the role of advance directives. It was widely recognised by most participants that not all nurses would be comfortable or wish to become involved in advance directives; it may be a role assumed by only a few nurses within a practice. Rachel speaks to this idea:

Rachel: *So maybe you would have specific nurses that did it [the role in advance directive communication], rather than every nurse had to do it. You know, you really want people to have an interest in it, and a real belief in it. Mmm.*

Lesley: *So I think it doesn't . . . I don't think it needs to be one nurse. It may be a couple of nurses . . . it's got to be a practice nurse who has the specialist interest in that arena, but also has the academic acumen behind them to provide that service.*

In contrast, one participant argued that when nurses choose to work with the public, they should be able to provide a full service to their patients regardless of personal beliefs. She understood that advance directives and palliative care were based on two different concepts; however, she acknowledged a concern that the meaning of advance directives could become confused with the meaning of palliative care.

Summary

Overall the participants clearly signalled that there is a potential role for primary health nurses in advance directives. Chapter Five discussed the challenges that need to be overcome for nurses to be involved in advance directives. In this chapter, participants specified the positive aspects that could facilitate the primary health nurses' role in advance directives. These aspects included nurses' attitudes, influences, and their nurse–patient relationships. Participants made suggestions as to what this role in advance directives could look like and how the role could be established.

One participant was personally not in favour of advance directives and was unsure of their value for Māori, raising the need to investigate this point further in later

studies. However, most participants from this study had favourable attitudes towards advance directives.

The participants identified a number of influences that contributed to these favourable attitudes. Some participants had been witness to a peaceful death as a result of the patient's wishes being met; others were witness to a death they believed could have been more peaceful if the wishes of the patient had been known. Other strong influences included cultural beliefs attributed to the Māori culture and/or the culture of nursing. Still others acknowledged that the length of time they had been practising influenced their views on advance directives.

Further to this, well-established nurse–patient relationships built on trust were identified as important to advance directive discussions. These relationships give primary health nurses an insight into the patients' values and beliefs which is considered intrinsic to effective communication in advance directives to facilitate patient voice in end-of-life care.

Multiple ideas on what roles the participants believed were important for effective communication were condensed into teamwork, initiating and recognising patient cues, raising public awareness and keeping the process simple. The nurse's needs required for this role were identified.

Underlying the participants' attitudes and beliefs was a fundamental approach centred on valuing the person. This will be discussed in the following chapter.

Chapter 7: Valuing the Person

Introduction

This chapter discusses participants' altruistic intentions of honouring the patient in promoting advance directive communication. It describes their views on what they see as important to the patient to ensure their rights and choices are well informed and supported. The findings demonstrate how the participants' views on advance directives served to meet the patient's wishes in a way that supports the fundamental caring "core" of nursing. Caring is a deeply held value by nurses, shown to the patient by concern, empathy and respect, with special attention paid to the needs of the person (Brooker & Waugh, 2007). The underpinning factors of participants' experiences of advance directives include caring concern and the importance of the patient. These findings are presented in this chapter under patient autonomy, holistic care, communication, relationships and acknowledging the individual. Figure 7.1 represents a schematic summary of the themes and sub-themes for this chapter (see Appendix Q).

Patient Autonomy

For the participants of this study, respecting patient choice and patient autonomy aligned with the concept of advance directives. These principles were practiced in their nursing role irrespective of their own personal beliefs. Patient rights and patient choice are intertwined in respect to patient autonomy (Blondeau, et al., 2000) and are associated with individually tailoring advance directives to the person. Furthermore, it was evident that respecting patient choices and patient autonomy was important to the participants' overall care of their patients. These factors represent core values of their profession and were evident through many of the participants'

responses about primary health nurses' attitudes, experiences and knowledge of advance directives. Patient choice is discussed first.

Ensuring patients had freedom of choice was overwhelmingly supported as a core value by most participants. This is illustrated by Anita and Denise when discussing patient choice:

Anita: I do think it's a person's choice, and I'm for the most part happy that they . . . as long as they are informed of their options, and the results of their choices, then I'm fairly happy for it, to accept their choices. . .

Denise: . . . So to me if that person is quite clear in their mind and not coerced obviously or anything and it's an individual independent choice to do it, I think go for it.

Patient choice is not only characterised by the potential for creating advance directives but patients recognising their ability to change their mind or opt out of an advance directive at any stage:

Harriet: . . . the patient should be able to change their mind obviously, 'cos they might decide they don't want to do whatever and when it comes to it, they do want heroics. . .

Narelle: . . . I mean we can't make people make the choice; it's their choice, individual choice. That day it may be what they want, another day, they may change it. That's up to the individual.

Participants recognised patient choice is also about respecting patients' individuality, recognising that they may vary in their decisions to become involved in advance directive discussions. Some will wish to be involved in these discussions while others will not. A number of participants identified this aspect, conveyed in the

following responses:

Bronwyn: . . . *I don't know that everybody would want an advance directive.*

Richard: . . . *I don't think they should be a requirement . . .*

Heather: . . . *It's something that ought to be . . . maybe it needs to be looked at and introduced as a topic but not set in concrete.*

Some participants talked about respecting the patient's right to have the treatments they desire, and a right to have some control over their end-of-life care.

The following responses describe the acceptance of patient rights:

Jill: *I accept whatever other people want as their right. It's their right . . .*

Bronwyn: . . . *People have got a right to the treatment they want . . .*

Harriet: . . . *I think we need to have a bit more control over it [end-of-life] . . . it's part of your life and you should have a bit of say in it . . .*

Similarly, one participant suggested that patient choice is also about allowing treatment interventions to be made available for all, regardless of age:

Lesley: . . . *you hear about the 85-year-old that's gone into hospital, and gone under full resus . . . then dies two weeks later through a chest infection, for example . . . If that's her choice, that's her choice. So we shouldn't just have an advance directive to say "do not resuscitate this 85-year-old", if it's not her choice type scenario. That the health dollar should not come into it at all . . .*

An important aspect of patient autonomy was the idea of maintaining a 'voice' with advanced directives despite not having a physical voice. Libby and Diane described the importance of individuals maintaining a voice:

Libby: *Pretty much that people can still have a voice when they don't have a physical voice anymore . . . It's really important.*

Diane: *I think it very much then would ensure that if I was incapable of having a voice . . . that my voice was still there somewhere heard around the table, particularly if it was about me. I think that's very important, knowing that other people have completely different perspectives on life and issues than me.*

The concept of maintaining a voice in advance directives was felt to be particularly relevant to the elderly. Denise and Libby shared their views on the elderly being marginalised in that it seems their choices or rights become less and less. They suggested that advance directives may open up further communication for such patients. These ideas are illustrated in the comments below:

Libby: *You know, you are your own person, once you reach 18, 19 whatever, you're kind of your own person and you're expected to behave in certain ways and you're expected to make a life, and suddenly you get to 80, and you're incontinent and sometimes you forget what we're talking about, and so it's almost like you've got no rights any more after that.*

Denise: *. . . I have seen a lot of patients that have gone from these strong, independent people to just shadows of themselves, and that aging process can be difficult for some people – easier for others . . . where their rights just get whipped away and you just think it would be better to, if that was an open discussion when you were well, and a well-prepared discussion instead of because I've done it too late for you to make that . . .*

These participants' comments demonstrated the depth of their compassion towards the elderly. They clearly portrayed the concept of care considered integral to nursing. This care and concern is an underlying principle of patient autonomy, a central

component of advance directives. Rachel summed up the importance of patient autonomy relating it to current attitudes towards the healthcare system of today:

Rachel: . . . *I think it is a huge part of autonomy for people. And I think that's what people are looking towards now, with healthcare.*

The inherent respect for patient autonomy and patient choice was evident in the care and compassion reflected in the participants' comments. It appears that these core values guide the participants' ethical nursing practice. These beliefs and values they bring to their role are what guide their attitudes towards advance directives.

Holistic Care

Holistic care is a core value of nursing. It is care that involves looking after the "whole person", recognising their uniqueness and incorporating the physical, psychological, social and spiritual dimensions of that person (Brooker & Waugh, 2007). Providing holistic care underpinned the participants' attitudes towards their role in advance directives. Providing care and maintaining the dignity of the individual and their whānau/family is intrinsic to holistic care and aligns with Watson's Theory of Human Caring. Many participants related how important the care and dignity of the patient is in respecting their wishes and values. Participants' suggested advance directives contribute to holistic care and maintain the patient's dignity in end-of-life planning:

Harriet: . . . *I think it [advance directive discussions] would be a good part of the holistic care that we give . . .*

Narelle: . . . *it's [advance directives] around the individual, it's what they want, not what the family wants . . . but it is supporting the family and being able to*

inform them of those decisions, probably building up support within the family, advocacy and ensuring that the individual has been able to have rights . . . ; it's about that dignity and that respect and that caring . . .

Diane: . . . *I have quite a holistic view . . . it's [advance directives] actually about the decisions around degree of intervention . . . and the length of intervention in terms of the difference between alleviating comfort and taking care of things, around dignity as opposed to withdrawing things, necessarily.*

Likewise, Libby, who tended to think advance directives were wide, encompassing all that is important to the individual as a whole, talked about her personal ideal to support the whole person in her role as a nurse:

Libby: . . . *I can hold onto my ideals when I'm in here [her workplace]. I think that you have to allow people to be who they are all the way. All the way . . .*

Furthermore, caring stretches to other work colleagues; an important cultural concept, often taken for granted but not necessarily verbalised to others. Richard took into account the doctors' busyness:

Richard: . . . *The other barrier is time. You know, thinking about one of them [the doctor], who does carry more than his share of the load, he hasn't got time to be mucking about . . .*

Lesley talked about how unfair it is to ask doctors to sign an advance directive if they are not familiar with the patient:

Lesley: . . . *Which is unfair, to ask a GP to do that, for the fact of sometimes when people go into care, it's not their long-term GP. It may be their new GP, that doesn't know that patient's history . . . I'm sure they do know their medical history . . . but they don't know that long-term history, or the family dynamics that may have gone on.*

Others acknowledged not all nurses may want to be involved in advance directive communication; nurses need to be accepting of differing beliefs and individual strengths different people have. Consistent with these beliefs, Harriet introduced a new idea demonstrating the need to have an instant supportive backup for staff and patients, should any unforeseen issues arise:

Harriet: . . . *if you started talking to someone and they suddenly have a complete meltdown and you've got three minutes, you can flick them for support about whatever issues they've got on and you haven't suddenly got to deal with whatever, whether that's Hospice support, or nurses' support or whatever, I've got no idea, but if there's something to support our nurses in that situa . . . and our doctors . . .*

Communication

Lesley: . . . *But the most important part is, is about communication . . .*

Lesley's comment succinctly and accurately summarises this section on communication. According to Libby, knowledge is power; thus good communication is multi-layered, cuts across many dimensions and is about empowering and valuing people. Patient centred communication has been found to be linked to empowerment and an improved self-rated overall health (Rohrer, Wilshusen, Adamson, & Merry, 2008). This section focuses on listening, checking for understanding, picking up on cues and clues, informed consent, and conversations among families, doctors and nurses.

Listening is one of the most important factors in communication. Therapeutic listening in the nurse–patient relationship is important in gaining a deeper

understanding of what is being said. It involves empathising with the patient, focusing on what he or she is expressing in order to problem solve (Brooker & Waugh, 2007) and meet their needs. Listening enables the nurse to learn about patients and their values and is considered to be a caring behaviour (Gallagher-Lepak & Kubsch, 2009; Gregg & Magilvy, 2004); listening is one activity that provides a foundation for implementing Watson's carative factors (Gallagher-Lepak & Kubsch). Listening may be intuitive, in hearing what the message really is, as opposed to what may be being said on the surface (Seidman, 2006). Active listening enables the nurse to pick up clues in establishing the patient's readiness to discuss advance directives. It can also include listening out for rash decisions being made. The following comments illustrate the importance of listening:

Lesley: . . . *she [the nurse] is going to be a listener . . . you know, sometimes the patient may make a decision too quickly, which isn't to their advantage, of what they really want at the end of the day. So I suppose it's about knowing that gut . . . using your gut intuition . . .*

Bronwyn: . . . *So encourage them to discuss it [advance directives] with the GP, listening for those clues and getting something established . . . so it's knowing them [patient], listening to them, what did they want, being able to advise them, and know where to send them for advice, starting with the GP. . . .*

Narelle: . . . *It's [advance directive communication] preventing stress, preventing grief, preventing problematic situations from . . . coming from anywhere . . . It would give them peace of mind . . .*

Participants identified listening and clear sensitive communication as important not only with the patient but also with their whānau/families. They believed this

enabled whānau/ families and/or friends to know what the patient really wanted at their end-of-life:

Narelle: . . . *It's [advance directive] communication, good communication and allowing people to have their own opinions, and allowing families to have their opinions . . . it's people's choices whether it is good or bad.*

Richard: *I think that could work in general practice with advance directives. If you had the appropriate legal document, and you sat down with the patient and their relatives, whatever the advance directive was . . .*

Rachel: . . . *it is extremely important that people discuss it [advance directives] early, and raise it regularly with their families, so there are no surprises for the family . . .*

Harriet and Diane both believed that having in-depth conversations about advance directives enabled people to consider what is important to them. Moreover, conversations among people about advance directives may enhance a deeper understanding of each other and identify differences not only on a personal level but possibly on a cultural and community level in regard to attitudes to death and dying. This is reflected in Diane's comments:

Diane: *I think these sorts of conversations [advance directive conversations] add layers to our understanding of each other, too, and these sorts of conversations raise issues around the differences as well, even culturally between people and communities. Because I can imagine these things bring up issues around, different cultural practices around death and dying and those sorts of things, so I think it is timely to go there.*

Furthermore, in-depth conversations between nurses and patients about advance

directives enable adequate information to be shared. Adequate information reduces misunderstandings and is essential for informed consent required in advance directives. Ensuring the patients and family are fully informed and allowing time to discuss things amongst themselves and with their primary health team is crucial in avoiding misunderstandings. Heather stressed the need to have these discussions with families and doctors and taking adequate time for decision making. Aligning with this concept, Bronwyn, along with others, also stressed the importance of informed consent:

Bronwyn: . . . *I think it's [advance directives] part of informed consent, which plays a big part of the primary care role. How do you know what decisions you're going to make if you're not informed, and if you feel strongly about something?*

In contrast, Pamela, who was unsure of the value of advance directives, firmly believed communication and providing adequate information was the main goal for end-of-life cares. She stressed the importance of ensuring whānau/families are well-informed and have full understanding of what may be involved in their care. Ensuring they are fully informed empowers the whānau/family while at the same time giving them a sense of being supported and cared for. This type of communication is foundational to Watson's Theory of Human Caring which includes valuing the patient:

Pamela: . . . *I've got a really strong sense that they [families and particularly whānau] need to be well-informed. And it's not just informing them, but making sure they understand what you're saying.*

Supporting patients through informed decision making is paramount in advance

directive communication, as illustrated in Pamela's comments:

Pamela: . . . *I'd have to make sure they're [the patient] well supported for that [advance decision made by the patient] decision. And it's their decision; it's not something enforced on them . . .*

Rachel: . . . *The nurse, her role is to support that patient while they're writing. You know, maybe when they've gone to see their GP . . . and that nurse, you know is their advocate, but also sitting there alongside them, and ensuring that their wishes are written down correctly.*

However Pamela, who personally did not believe in advance directives for herself or her family, reasoned that as long as there is a good understanding of the situation, families on the whole make the best decisions without advance directives as a result of clear direction from the attending medical team. Pamela's comments capture this view:

Pamela: . . . *So I think so long as the family are well informed, then they will, on the whole, make decisions best for that family . . . So without advance forms [advance directives], but also with clear direction, they can make decisions.*

Although one participant was unsure of the value of advance directives, all participants recognised that clear sensitive communication was essential to advance directive discussions. These in-depth discussions enhanced and underpinned the respect participants' accorded to the individual.

Acknowledging the Individual

Respecting the individual and acknowledging their uniqueness reflects the value nurses' place on their patients. The participants revealed a number of

characteristics and attitudes for nurses to enable patients to feel valued. These characteristics and attitudes include respecting patients' feelings, respecting their wishes, recognising their needs, and respecting their perspectives. It also requires the nurse to put aside his or her own biases where necessary.

Being aware of one's biases was seen as significant in enabling effective advance directive discussions. Maintaining an open mind without preconceived ideas is inherent to helping patients in advance directive discussions and promoting effective care (Jezewski et al., 2003); this also aligns with Watson's Theory of Human Caring. A number of participants raised this idea:

Lesley: . . . *She's got to be unbiased. That's probably the key, is the nurse has to take away her values and beliefs and become biased to what the patient wants.*

Bronwyn: . . . *if you had a nurse with strong views about something, I think that would be a hindrance too. It's got to be impartial.*

Several participants identified the significance of the different perspectives we all come from, suggesting care needs to be taken not to make presumptions or interpretations about the patient's and/or family's ideas. Bronwyn encapsulated this view further stating "it's the patient that's the centre of care".

Accepting and recognising the patient's perspective plays a large part in acknowledging the individual. Rachel reiterated the importance of advance directives in honouring what a person desires. Another participant believed that patients should be in charge of their own body. He suggested nurses need to recognise the patient's needs prior to raising the idea of advance directives with him or her. Effective interpersonal communication skills and involving the patient in his or her care are

underpinning principles of person-centred practice (McCance, Slater, & McCormack, 2009); both are essential in developing caring relationships. The following comments demonstrate the importance of recognising the patient's perspective:

Libby: . . . It's [respecting the patient] all about what the person's needs are. And I think if you are a good primary health nurse you're helping people identify their need . . .

Rachel: I think the most important aspect of an advance directive is that it honours what the person would want . . .

Several participants acknowledged it is their respect for whatever the person believes in that enables them to support advance directive discussions. Libby's comments add further clarification to this as she discussed people with definite spiritual beliefs:

Libby: . . . I am not very spiritual but there are a lot of people out there who think that if what you wanted at your time of death wasn't done right, those people believe those souls will be tormented. So I think it's something really important about that.

Part of respecting the individual is also respecting their family's values and opinions, their culture and surrounding community. New Zealand nurses are expected to practice cultural safety with Nursing Council standards, guided in particular by the Treaty of Waitangi and principles of participation, partnership and protection (Nursing Council New Zealand, 2002). Advance directives are considered to be individual choice; however Māori culture focuses on whānau/family decision making:

Richard: . . . *I think you would really have to have a Māori family on board if an individual wishes to make a . . . and they would have to help with that. So it would be a family decision in the case of Māori, and probably the Pacific Islanders . . .*

Treaty of Waitangi principles appear to be embedded in the participants' nursing practice. A number of participants recognised the importance of Māori values, suggesting one size does not fit all. Furthermore Rachel suggested Iwi (see Glossary p. 212) may raise these discussions about advance directives and give direction as to how best meet their needs. Cultural competence can only be practiced when the nurse has effective communication skills and developed relationships with their patients.

Relationships

Therapeutic relationships allow the nurse and patient to work together to identify issues requiring change and facilitates the patient to their maximum strength (Brooker & Waugh, 2007). These relationships are developed over time and place the nurse in a unique position to foster patient confidence in advance directive discussions. Nurses are then in a position to be able to support and advocate for their patients' choices. These therapeutic nurse–patient relationships enable the patient to feel supported and valued as a person; reflecting the values of Watson's Theory of Human Caring (Jesse, 2010) .

Building meaningful relationships helps build patients' confidence in sharing values and ideas that are important to them. Narelle discussed the nurse's caring role and the importance of building and nurturing trust with patients, recognising this is

intrinsic to raising advance directive discussions. Harriet's comments summarise the importance of the nurse–patient relationships:

Harriet: *Well we've got that long-term relationship with the patients. That's the guts of it, is that we actually see our patients, we know them quite well, so we can have those [advance directive] conversations . . .*

One participant identified that her relationships with patients were more stable in her practice as there was a high turnover of doctors in her locality. This high turnover was seen as a barrier to advance directive discussions, with the participant suggesting those nurses who have stable nurse–patient relationships may have a role in advance directive discussions:

Jill: *I think in our practice the nurses know the patients better because we have quite a large turnover of doctors . . .*

[Int: . . . I'm understanding that you see there could be a role for the primary health nurse in this [advance directive communication]?]

Jill: *Well I think at our practice there could be, because of the high turnover of doctors . . .*

Denise also acknowledged the importance of these relationships, suggesting advance directive discussions are not suited to urgent care practices where the patients are often unknown. She expanded on this idea suggesting nurses need to be confident in their practice with advance directives and their nurse–patient relationships prior to raising the topic of advance directives:

Denise: *. . . you'd have to be quite confident in your practice and confident in your relationships with the people you were bringing it up [advance directive communication] with.*

In addition, Diane believed that discussing the topic of advance directives can further develop relationships by discussing matters on a deeper level. She suggested these deeper relationships would result in better healthcare being offered:

Diane: I think we can more and more offer better healthcare support by getting below the surface of things more and more, and these conversations [advance directive conversations] do that because they challenge us to do it. Because it isn't just like asking someone the simple questions, it's a decision to engage on a deeper level and I think that's a good thing for us. It's not as easy. I think it engages deeper in relationships with people and I think we are meant to be doing that.

Established nurse–patient relationships may facilitate and empower nurses to act as suitable advocates for their patients. Advocacy is considered one of the caring-related interventions underpinning Watson's Theory of Human Caring (Gallagher-Lepak & Kubsch, 2009) pivotal in honouring patients' wishes. Many participants identified patient advocacy as an important element in advance directive discussions.

Rachel: . . . I think for the nursing point of view, you want to be an advocate for your patient. You want to do no harm, but you also want to honour the patient's wishes. And I think for . . . to be a patient advocate, I think that's really helpful, to have something like that [advance directive].

Denise: . . . if I knew the patients that had made those decisions that if it was brought up to make sure they were followed through. Then I would really push that it was understood and clearly followed through, I would try to push that to the family, to the caregiver or to the doctor . . .

Rachel and Libby further discussed the importance of advocacy for patients who are

terminally ill or cannot speak for themselves, suggesting advance directives maybe helpful to advocate for the patient in a time of family distress. Accordingly, they felt knowing the patient's wishes may alleviate some of these difficulties.

Discussion

This section was dedicated to discussing the findings of this chapter including a discussion of the concepts of autonomy, holistic care, communication, acknowledging the individual and relationships.

As identified by Jean Watson (2002), the “core” of nursing includes those factors of the nurse–patient relationship that result in therapeutic outcomes. These outcomes are a result of the caring process carried out by the nurse, which extends to a transpersonal caring process between the nurse and the patient. Caring is both complementary to and in contrast with curing. It is this combination that enables nursing to maintain its unique function in society (Watson, 2006). The participants' humanistic caring approaches influenced their attitudes towards advance directives in recognising advance directives as an integral component to holistic patient care. This was reflected in the way the nurses' valued their patients.

In discussing the primary care nurse's role in advanced directives the participants' responses exhibited a caring and qualifying endorsement of their role as caring nurses in this context of advance directives. This caring thread was evident throughout the study.

Summary

In this chapter I discussed the overarching theme “valuing the person.” The intimately held humanistic and existential philosophies associated with the “core” of nursing (Jesse, 2010) are reflected in the participants’ beliefs and values towards advance directives. The importance of patient autonomy, holistic care and effective communication in advance directive discussions was evident. These concepts were enhanced by well-established therapeutic nurse–patient relationships built upon trust and positive regard. A caring approach and sensitivity to patients’ values and beliefs were essential to developing these relationships, imperative for constructive advance care planning discussions. Participants affirmed that recognising all that makes the patient unique is fundamental to enabling the patient feel valued as a person. These findings will be discussed in more depth and conclusions made in the following and final chapter, Chapter Eight.

Chapter 8: Discussion of the Findings

My commitment to conducting this study resulted from my interest in palliative care and end-of-life issues in primary health. To maintain a focus for this study I decided to look at advance directives in the context of advance care planning in primary health. Advance directives have recently become a topical issue in New Zealand with a focus on improving individuals' end-of-life care, including respecting patients' wishes about the use of medical interventions to prolong life or not. Specifically, there has been no published literature produced in New Zealand regarding primary health nurses' involvement in advance directives. With an increasing amount of end-of-life issues being dealt with in primary health, there is a need to know where nurses are situated in regard to advance directives in order to build further research into advance care planning in primary health.

The purpose of this case study was to understand the primary health nurse's role in advance directives. A qualitative approach was used to gain an in-depth contextual understanding and develop insights into the situation and meaning of the phenomenon of inquiry. The research question was: What role do primary health nurses have in advance directives? Watson's Theory of Human Caring was used as the theoretical framework to guide this study.

The objectives were to:

- Explore and describe primary health nurses' general knowledge and attitudes relating to advance directives.
- Describe primary health nurses' experiences with advance directives.

- Describe the primary health nurse's role with advance directives in primary health.

Two propositions were identified through the literature and my practice experience; these propositions informed my analysis:

- Primary health nurses currently do not have a role in advance directives.
- Primary health nurses believe that advance directives can promote effective-end-of-life care.

The study was conducted in one province in New Zealand with thirteen senior primary health nurses. Data was obtained using semi-structured individual interviews.

The perspectives gained from the participants reflected their overall belief in the need for advance directives to ensure that patient autonomy is respected in end-of-life. They believed advance directives sat well in primary health and that the primary health nurse had a role to play in this. Results reveal, however, that for these nurses, their limited experience and attitudes towards advanced directives were fraught with challenges, complications and a lack of knowledge. Despite these challenges, the participants conveyed fundamental and genuine care and caring praxis for their patients in describing how primary health nurses could have a role to play. This care was demonstrated through their advocacy for patients, their desire to honour patients' wishes and ensure they were fully informed about all options available, and their strong notion of patient autonomy in their end-of-life care. These aspects of care were fundamental in their role as nurses and were integrated into their attitudes towards advance directives.

The following section is a discussion of the themes that emerged from my analysis: 1) encountering challenges; 2) facilitating patient voice; and 3) valuing the person. These are discussed in relation to existing literature. I will frame this discussion in terms of what is known about nurses and advance directives and how my findings confirm or build onto this knowledge.

The theme “encountering challenges” highlighted complexities associated with advance directives both in their generic form and in relation to the primary health nurse’s role. Underlying these challenges was participants’ desire to implement advance directives that were patient specific and relevant to the whole person – or to the patient’s goals, values, relationships, and culture. These challenges are illuminated below in a manner that demonstrates the richness of participants’ perspectives that were central to the analysis (Zucker, 2001).

Encountering Challenges

The primary health nurses interviewed in this study offered wide and diverse views as to their understandings of advance directives. They understood advance directives as ranging from “do not resuscitate” orders, to organ donation and burial, through to labelling personal belongings.

Participants in this study appeared to be uncertain as to whether an advance directive should be written or verbal. Most participants indicated an advance directive needed to be a legal document. Some indicated that advance directives could be patients’ verbal instruction about what their wishes were for end-of-life cares. Despite “advance directives” being a health term in New Zealand since at least 1995, several

participants were not familiar with the terminology but could identify a living will or power of attorney. This suggests the absence of discussions about advance directives among nurses in the primary health sector. Although most participants seemed to have some general knowledge about advance directives, they questioned their validity in terms of assuming they could be overridden by medical staff or family. A knowledge gap was evident among the participants about the legislation pertaining to advance directives; this finding concurs with the work of other studies focusing on the nurses' knowledge, attitudes and experiences of advance directives. These studies included nurses working in oncology, home health and general nursing personnel (Badzek, et al., 2006; Duke & Thompson, 2007; Jezewski, et al., 2005; Lipson, et al., 2004; Putman-Casdorff, et al., 2009).

The participants for this study were of diploma or bachelor degree level of education, with approximately half having a post graduate qualification. All had qualified as registered nurses prior to 2004. The general level of education did not appear to have a significant effect on the overall knowledge the participants had; this concurs with Lipson et al.'s (2004) findings about the knowledge, attitudes, and predictors of advance directive discussions of 719 registered nurses in the USA. This may indicate advance directive communication may not be a priority in nursing education. It could also be due to the relatively new concept of advance directives communication, which may not have been as relevant to the nursing education prior to 2004. The age and experience of the participants may also be a relevant factor in this New Zealand study, with all of the participants over 40 years of age with a minimum of six to ten years nursing experience. The fact that the New Zealand Nursing Council released in 2010 its first statement ever about advance directives gives weight to these

ideas. Other more recent studies on nurses' knowledge in advance directives have shown the level of education on advance directives correlates to the knowledge and the ability for nurses to have these discussions (Duke & Thompson, 2007; Putman-Casdorph, et al., 2009). Duke and Thompson conducted a survey on nurses' knowledge, attitudes and practices regarding advance directives. In their study, one hundred and eight nurses from two hospital facilities in Texas, USA completed a survey consisting of closed and open ended questions. Results indicated the nurses lacked an understanding and technical knowledge of advance directives. Their findings were particularly relevant to nursing education curricula as they identified no nursing continuing education regarding state laws, effective communication and completion of advance directives had been conducted in the five years preceding their study.

Most of the participants had limited or no experience with advance directives. Several had rest home experience with "do not resuscitate" policies, whilst only one participant recalled any other professional experience with advance directives. Only one participant had a role in advance directive communication in primary care. This was her first experience and had occurred only two months prior to these interviews. No other direct involvement was experienced by the remaining participants. In keeping with the results of my study, Putman-Casdorph et al. (2009) found in their evaluation of nurses' knowledge, attitudes, confidence and experience of advance directives, nurses lacked experience with advance directives. Eighty seven nurses who were based in a variety of inpatient and outpatient nursing roles had taken part in Putman-Casdorph et al.'s study. However, the findings from my study contrasted to Jezewski et al.'s (2005) study on oncology nurses' experience in advance directives. Their findings revealed most of their participants were experienced in assisting patients with advance directive completion.

This may be as a result of furthering education in the specialty area the participants worked in and the possibility it is an area where advance directive discussions may be seen as a priority in their care. As with a study by Jezewski et al. (2005) on oncology nurses' experience in advanced directives, participants' believed that more collaboration must occur between the nurses, medical personnel, and patients and their families to ensure patients' wishes are respected.

Several participants in my study were aware of advance directives being overridden by medical personnel and family members. Again, Duke and Thompson's (2007) and Jezewski et al.'s (2005) studies revealed a small percentage of nurses believe the physician or family members would override the advance directives. Several participants discussed the difficulty they faced when they knew of situations where advanced directives had been overridden by the family. Findings from research conducted in 2011, suggests nurses who were witness to ethical dilemmas, such as advance directives not being honoured, may find themselves in a morally challenging situation. Seventy nurses registered for an annual Ethics of Caring Conference in Los Angeles found this was the case, particularly in relation to medical professionals' and families' failure to honour patients' advance directive wishes (Pavlish, et al., 2011). The researchers had designed a questionnaire to explore nurses' descriptions of ethically difficult situations and found issues surrounding patient autonomy as one of the most prevalent issues.

Complexities identified as challenges to advance directive communication in primary health included when and how to introduce the topic to the patient. Most participants believed the earlier the topic was raised the better – for example, that the initiation of advance directives in rest homes or palliative care was too late. This builds

onto findings from Sankaran et al.'s (2010) initial evaluation of an intervention supporting Age Related Residential Care (ARRC) in New Zealand. In their study, staff believed initiation of advance care planning should begin when the older patient is living independently in the community. Other participants from my study believed advance directives could be introduced as an idea even as early as 20 years of age. While other participants thought 45–50 years may be appropriate to raise the topic of advance directives. Still others believed advance directives could be raised when patients developed chronic disease and/or co morbidities. However, Wissow et al. (2004) argue that older age is associated with a more positive response to advance directives. These results were identified by the researchers who had conducted a one year quasi-experimental trial designed to increase the uptake of advance directives at five health centres in one region of a large managed care organisation in the USA. The research was limited in that it was restricted to individuals over 65 years of age, who were ambulatory, and had a health maintenance visit with their primary health provider during the study year. Furthermore, a qualitative study in the United Kingdom (UK) conducted with twenty two palliative and oncology patients revealed many patients thought it more appropriate to have advance care planning discussions when treatment had failed or the prognosis was poor (Barnes, Jones, Tookman, & King, 2007). These studies support the complexities and difficulties participants in my study identified as to when the right time may be to introduce advance directives.

In addition, several participants in my study believed that nurses should identify cues from patients in order to raise the topic; one participant suggested nurses only raise the topic when asked. Similarly, a survey carried out to determine patients' knowledge, attitudes and preferences about advance direct suggest 62% of the patients believe that it

was up to them to raise the topic; however, 70% reported they would be comfortable if the health provider initiated the discussion (Jackson, et al., 2009).

Multifaceted cultural beliefs were also seen as challenges needing to be addressed. In particular, participants acknowledged the importance of meeting the needs of Māori and Pacific people; Rachel identified “not one size fits all.” This indicates the importance of advance directives being individually developed to patients’ needs in a form that is acceptable to them. Auer (2008) recommends that “attention to cultural differences in end-of-life discussion could improve existing disparities to minorities (p. 188) in end-of-life care. One participant, who identified herself as Māori, acknowledged she was unsure if advance directives were appropriate at all to Māori and did not see the concept of advance directives fit with her cultural values. However, she stipulated that this was her view and not necessarily that of all Māori nurses. Crane et al. (2005) believe the effect culture has on advance directives is relatively unknown, therefore further cultural evaluation is required, especially in multicultural societies, such as New Zealand. Incorporated into cultural complexities are the varying attitudes toward death between different cultures.

Several participants suggested that death appears to be a taboo subject and is not often openly discussed amongst New Zealand Europeans. Other participants highlighted that Māori seem more comfortable with the idea of death and acknowledge the normality of death; this idea is affirmed by a New Zealand Māori nurse author (Clair, 2006). This finding is congruent with findings from a survey conducted in the USA on health professionals’ advanced directive communication that suggested health

professionals' practice in advance directive communication correlates to their experiences and attitudes towards death (Black, 2007).

The participants recognised the possibility of diverse communication complexities that may occur with advance directives. Communication issues within families were identified, for example, in the event of patients withholding information from some or all family members or the possibility of coercion by family members. A questionnaire by Sahm et al. (2004) on patients' and health professionals' attitudes and barriers toward advance directives revealed concerns held by the participants on the potential abuse of advance directives and possibility of coercion of patients into writing an advance directive. This finding was also supported in a British qualitative interdisciplinary study of health professionals' views on advance directives (Thompson, et al., 2003).

Issues surrounding inadequate advance directive communication within the participants' own workplaces were also raised, for instance when information was not shared. This finding is supported by Jezewski et al. (2003) who suggested there was a need for improved communication and collaboration within the health team. Furthermore, fragmentation of technology and communication breakdowns across the health field to secondary services, such as accident and emergency services, were identified by the participants as problematic. These represent situations where there is a potential for patients with an advance directive to not have their wishes observed if information is not transferred to appropriate personnel providing emergency and/or end-of-life care.

Advance directives should not be ambiguous for health personnel providing end-of-life care. The participants acknowledged that advance directives need to be individually tailored. They suggested broad advance directives may create problems; health professionals may find it difficult to ascertain patients' wishes in end-of-life care if the directives were not clear. Some suggested advance directives should be situation-specific. A study of one hundred files of deceased nursing home residents reviewing specificity in advance directives identified the importance of specificity in advance directives for elderly healthcare (Pekmezaris, et al., 2004). The results showed that specificity was a determinant in predicting the site of death for those end-of-life patients, supporting the findings in my study about the need that advance directives be specific. However, Pekmezaris et al. cautioned that such specificity in advance directives may not be appropriate for the general population; according to Brett (1991), specificity may deflect attention inappropriately from treatment goals (as cited in Pekmezaris, et al.) Thompson et al. (2003) acknowledged the difficulty faced in fully informing people about possible health challenges they may or may not be faced with in the future; this concept was raised by several participants in my study. Indeed, some participants recognised challenges that may occur as patients' ideas may change when faced with different scenarios of ill health or impending death; this is supported in other literature confirming that patients may change their ideas about advanced directives as their health status changes (Ditto, Jacobson, Smucker, Danks, & Fagerlin, 2006; Wareham, et al., 2005).

Further challenges denoted by the participants were a number of barriers pertinent to advance directives in primary health. The most pressing issue was identified in terms of a lack of time for nurses and medical staff. This was a finding in a number

of other studies, which suggested a lack of time is a barrier to advance directive discussions (Badzek, et al., 2006; Jezewski, Meeker, & Schrader, 2003; Ramsaroop, et al., 2007; Tierney, et al., 2001; Wissow, et al., 2004). Some participants believed that timing issues could be addressed by using a screening tool or by incorporating advance directive communication into nurse clinics. These study findings were confirmed by Resnick and Andrews (2002) who conducted a descriptive study of 135 adults living in a retirement community. The participants of their study highlighted the importance of allocating adequate time for advance directive discussions.

In addition, physical factors such as a suitable environment and privacy for advance directive communication to be held were identified as potential barriers. A number of workplace environments consisted of cubicles with some side rooms designated for more private procedures or assessments to be carried out. However, two participants reported that such rooms were shared by a number of practitioners and may not always be available. Other participants had their own designated rooms for private conversations. The participants came from ten differing work environments therefore did not all have the infrastructure to support advance directive discussions. Other physical factors may include monetary issues. Several participants wondered how the nurses' time for advance directive discussions could be funded. The participants from my study acknowledged that general practice is not only a service but is also a profit making business which could raise issues about funding of nurses' time for advance directive discussions. These comments allude to the possible structural difficulties in primary care to meet the needs of their specific populations. For example, the National Primary Medical Care Survey, conducted in New Zealand between 2001 and 2002 with a nationally representative group of general practitioners and nurses, investigated the

capacity of both non-governmental primary care organisations and traditional based primary care teams to carry out population based care (Crampton, Davis, & Lay-Yee, 2005). Findings from Crampton et al. (2005) suggested the traditional based primary care teams may not best be able to meet the needs of the population because it may go beyond their means to fully respond to the needs. These findings support the views of the participants who wondered how advance directive discussion could be funded.

Participants identified other more non tangible potential barriers including language difficulties for those for whom English was not their native tongue. Participants noted that health professionals' personal beliefs and attitudes may create reluctance to become involved advance directive discussions. This reluctance may be attributed to health professionals' values or to their denial or discomfort experienced when discussing death. Furthermore, my study revealed that health professionals may not be adequately prepared to discuss advance directives. This has the potential to create a lack of staff cohesion and hinder advance directive discussions. These findings are consistent with barriers found in Ramsaroop et al.'s (2007) review of studies designed to increase the uptake of advance directives in primary care. Ramsaroop et al.'s findings indicated patients, families or health professionals' reluctance to discuss end-of-life cares were also potential barriers for advance directive discussions. Further in support of the findings in my study, Barnes et al. (2007) reported the need for health professionals to be informed about advance directives in order to be able to initiate these advance directive discussions (Barnes, et al.).

Facilitating Patient Voice

Participants' values and experiences in caring for end-of-life patients were key factors in determining their attitudes towards advance directives. All except one participant in this study had positive attitudes towards advance directives. These findings are in line with findings from other studies (Blondeau, et al., 2000; Duke & Thompson, 2007; Jezewski, et al., 2003; Lipson, et al., 2004), which identified nurses as predominantly having favourable attitudes towards advance directives. All participants in my study believed they had a role to play in advance directives; this confirms results from Jezewski et al.'s (2003) study on oncology nurses' attitudes toward advance directives. Participants in my study also believed that advance directives empower patients to maintain some control over their life should they become incapacitated to make end-of-life decisions. This finding aligns with the results of other studies (Blondeau, et al.; Duke & Thompson; Jezewski, et al., 2003; Thompson, et al., 2003).

Positive or negative personal and/or professional experiences in caring for end-of-life patients contributed to the participants' positive attitudes towards advance directive communication. This positivity occurred as a result of witnessing a peaceful death when the decedent's wishes had been met. It also resulted from being witness to a death they believed could have been more peaceful if the wishes of the decedent had been known. Participants believed that advance directives may have helped the patient achieve a more harmonious death. This confirms Thompson et al.'s (2003) findings suggesting one of the strengths of an advance directive is that it supports patient autonomy in allowing the patient to spend their final days in a manner harmonious to their wishes.

Several participants stated that the number of years they had been nursing had influenced their attitudes positively towards advance directives. They had been exposed to many different circumstances over an extended length of time. This finding was congruent with Jezewski et al.'s (2005) results, suggesting attitudes were affected by the number of years nurses' had been practicing. Cultural and religious influences also contributed to participant's attitudes, with culture seemingly playing a more dominant role with Māori participants. Cultural influences stemmed from the Māori culture, the nursing culture and/or the culture of the family. These influences contributed to the overall attitudes towards advance directives. According to Wareham et al. (2005) advance directive decision making is much more complex in the Māori culture where collective decision making is seen as more important than individual decision making. Wareham et al.'s article focused on the cultural dimensions, legalities, consumers and providers' perspectives, and the medical and nursing positions in advance directives in New Zealand. They note that historically New Zealand nurses have had a minimal role in advance care planning but should expect to have a more active role in the future. This aligns with the attitudes of the participants in this study who recognised how the culture of nursing had influenced their ideas. Several participants also discussed how their own family culture, consisting of beliefs and experiences they had grown up with, had influenced their attitudes towards advance directives.

As with Thompson et al.'s (2003) qualitative study on health professionals' views of advance directives, all participants from my study believed that primary health was an appropriate setting for advance directives. The participants saw advance directives as a venue for addressing issues such as patient choice and autonomy in end-of-life issues; they believed this was part of the holistic care they offered to their

patients. Well-established nurse–patient relationships were also seen as essential to advance directive discussions. In their article on individual preferences and availability of care for patients at end-of-life, Munday et al. (2007) expound on the significance of the general practitioner or nurse in regard to the choice and place of death for patients. They emphasised the importance of well-established relationships with patients and the ability to provide on-going relational continuity in end-of-life care. The importance of well-established relationships in advance care planning in end-of-life care is confirmed by Ramachandran (2008) who investigated the challenges primary health face in palliative care in non-malignant diseases. Ramachandran believed these relationships facilitate advance care planning discussions.

Nurses' empathy, congruency and warmth are identified as central characteristics that help build therapeutic relationships (Watson, 2006). The nurse's personal belief system and values are integral to the way they develop therapeutic relationships with the patient and others (Watson). Sensitivity to self and others enables the nurse to become authenticated; the participants in this study showed characteristics of immense empathy, congruency, warmth and sensitivity to their patients. According to Watson, these characteristics facilitate self-actualisation and self-growth in those with whom he or she interacts. It is through building these humanistic and existential characteristics that the nurse is able to fully reach out and care in a holistic and meaningful way for the patient. Well-established relationships built upon trust and positive regard give primary health nurses insight into the values and beliefs of the patients, identified by participants as essential in advance directives discussions.

Participants believed there is a potential role for the primary nurse in advance directives. For this role to be effective, team decisions, role delineation and team embracement of the concept were important. Teamwork was highlighted by a number of participants as instrumental to the implementation of advance directives. Participants identified the need to develop a mandate about the importance of advance directives and what it may mean for workforce development. In addition, they identified the importance of acknowledging what role each member of their health team has to play. Results from an American study about elements of successful advance directive programmes concurs with this finding, reiterating the importance of successful integration of policies, procedures and teamwork (Hickman, et al., 2005). Primary care nurses' roles identified by the participants in my study included initiating conversations about advance directives, and recognising patient cues for readiness to have these discussions. The participants believed integration within health professionals should result in the doctors' completing the advance directives or in the case of an enduring power of attorney, a lawyer.

Several participants believed raising public awareness as important to render advance directive communication more acceptable to the public. This is congruent with other studies (Jezewski, et al., 2003). For example, Later and King (2007), two American critical care nurses who provided a community education symposium on advance directives, had high attendance rates at both sessions, suggesting significant interest in the topic. However, there was no follow up to determine how many of the attendees' completed advance directives. Westley and Briggs (2004) suggested more community education was necessary for a potential behaviour change model to be used to improve communication in advance care planning. Findings from a qualitative study

by Jezewski and Meeker (2005) of chronically ill patients' perspectives of advance directives indicated the need to raise awareness and educate the public about advance directives.

Other participants talked about keeping the advance directive process simple. Auer's (2008) findings from her single case study on adults with chronic illness suggests advance directive discussions with the patient could occur when the patient is well. She identified that patients' three-monthly chronic illness visits to the doctor may be an appropriate time for this to happen. Similarly, the participants from my study identified the appropriateness of discussing advance directives during the three-monthly care, plus visits or other existing health maintenance programmes. The participants viewed advance directive communication as a process. This would ensure that patients receive adequate information to make informed decisions. This argument for advance directive communication to be a process is supported by Ramsaroop et al. (2007) who conducted a systematic review of studies designed to increase the uptake of advance directives in primary care. They found iterative visits with a health professional provide repeated clinical discussions which have been found to be effective in completing advance directives in primary care.

A number of participants identified patient advocacy as a key component in advance directives. This concept is well supported in the literature (Blondeau, et al., 2000; Jezewski, et al., 2005; Jezewski, et al., 2003; Wareham, et al., 2005; Westley & Briggs, 2004). The participants saw this role as providing support for the patient, helping them identify their values, and speaking out so their voices may be heard should the patient be in a diminished capacity to provide this voice. This concept of advocacy

identified by the participants aligns with Bu and Jezewski's (2006) findings of what patient advocacy is. The authors conducted a synthesis of literature between 1974 and 2006 examining the general concept of patient advocacy. They identified three core features of advocacy: safeguarding patients' autonomy, acting on behalf of the patient and ensuring social justice prevails in healthcare.

Support for nurses

Participants identified a number of factors that would help pave the way for primary health nurses to play an effective role in advance directive communication. The most dominant factor appeared to be education around advance directives and the legalities surrounding them. Many studies about nurses and advance directives have identified the need for nurses to have more education about advance directives (Badzek, et al., 2006; Blondeau, et al., 2000; Brown, 2003; Jezewski, et al., 2005; Jezewski, et al., 2003; Lipson, et al., 2004; Putman-Casdorff, et al., 2009; Ryan, et al., 2001). The participants in my study acknowledged that nurses require administration, medical and team support to develop effective advance directive discussions. These findings were consistent with the findings of Jezewski et al.'s (2005) findings in their study on advance directives and oncology nurses. The participants from my study further identified the need for effective leadership. Other factors identified by participants were adequate resources and clear guidelines – these align with the findings of Putman et al. in their study of nurses' knowledge, attitudes, confidence, and experience in advance directives. The researchers found that the nurses were lacking resources required for nurses to be prepared for advance care planning discussions.

The participants of my study further suggested certain nurse attributes were necessary components for the primary health nurse's role in advanced directives. These included the nurse having an interest in end-of-life care and the need to be a skilled communicator; in particular a good listener.

Valuing the Person

The third theme identified in the study relates to the “core” of nursing, or those factors of the nurse–patient relationship that result in a therapeutic outcome (Watson, 2001). This outcome is as a result of the caring process of the nurse, which extends to transpersonal care between the nurse and the patient. Caring is complementary but in contrast to curing. It is the combination of both that enables nursing to maintain its own unique function in society (Watson, 2006) and the humanistic and existential nursing philosophies of today. The participants' humanistic caring approaches influenced their attitudes towards advance directives – advance directives were seen as an integral component to their holistic patient care. This was reflected in the way the participants described the care they gave illustrating how they valued their patients.

In discussing the primary care nurse's role in advance directives, the participants exhibited a caring and qualifying endorsement of their role as caring nurses in this context of advance directives. This caring thread was evident throughout the study. The major concepts identified in this third theme were patient autonomy, holistic care, communication, relationships and acknowledging the individual. Each concept is discussed in turn.

Findings from Thompson et al.'s (2003) study about health professionals' views on advance directives suggest that advance directives are considered an effective agent of autonomy. Participants recognised patient autonomy as part of a fundamental and existential belief in respecting the patient's wishes, regardless of the nurse's own biases and beliefs. It is not just about respecting patient choice but about respecting the principles of justice and ethics intrinsic to nursing. Blondeau et al.'s (2000) findings, in their study of 306 Canadian nurses' attitudes towards advance directives, suggest that respect for patient autonomy is a determining factor in how the nurses' viewed advance directives. The sample was made up of 306 nurses working in a long-term care centre or a hospital centre. Blondeau et al. suggested that respecting patients' choices and rights, as well as individually tailoring discussions about advance directives were important moral responsibilities. Participants in my study endorsed freedom of choice and the opportunity to change one's mind at any stage. The participants also endorsed the choice for patients as to whether or not they choose to become involved in advance directive discussions. Being authentically present was important to enable and sustain the belief system of the patient (Watson, 2006). The participants affirmed the role of advocacy and spoke of this in reference to their nursing code of ethics. Encouraging patient autonomy is considered part of the nurse's role. Nurses are expected to comply with legislation, act ethically, maintain standards of practice, and respect the rights of patients (Nursing Council New Zealand, 2009) Respecting patient choice and patient rights underpin patient autonomy; participants in this current study supported patients in their decisions to have some control over their end-of-life. Autonomous decisions enable patients to have a voice about their life when they are otherwise physically incapable of having one (Thompson, et al., 2003). In particular, several participants

commented on how they saw choices for the elderly being stripped away, highlighting the importance that the elderly be able to maintain a voice over their lives.

Holistic care is a core value of nurses; this involves showing care for the entire person, physically, mentally, spiritually and socially (McGee, 2005). Holistic approaches include supporting the patients' whānau/family as part of total patient care. The participants determined that advance directive discussions may be seen as part of holistic care they give to patients and their whānau/family resulting in dignity and peace of mind for the patient in end-of-life planning. This is consistent with Thompson et al.'s (2003) findings in their qualitative study on health professional's views on advance directives. Their findings suggested advance directives enable patients to gain peace of mind and allows them the choice to die in a manner in keeping with their values.

Holistic care also pertains to colleagues. This is a result of the culture of nursing; holistic care is a concept often taken for granted. Basic underlying assumptions are those that are never questioned but make up an important part of the nursing culture (Anthony, 2010). Care and concern was apparent for colleagues who struggled with the concept of advance directive communication or who may be called upon to become involved with no prior knowledge of the patient. This humanistic and holistic attitude conveyed in participants' stories is supported by developing and sustaining helping, trusting, authentic and caring relationships (Watson, 2006).

Effective communication

The importance of effective communication was woven throughout this study. In valuing the person, participants emphasised the importance of listening, picking up

clues, and checking for understanding to gain informed consent. Listening is one of the key characteristic of communication in holistic care (Brooker & Waugh, 2007) and was identified by participants to be imperative in advance directive discussions. This notion is supported by Jezewski et al. (2003) who identified the ability and willingness to listen as being crucial to advance directive communication. The participants from my study identified that listening enables the nurse to learn about the patient, what his or her values were, and to pick up clues as to when it may or may not be appropriate to discuss advance directives. They suggested that a caring approach and sensitivity to patients' values and beliefs enables patients to gain insight into what is important to them and communicate what their needs are. Knowledge of patient values and beliefs are key elements of advance directive discussions (Crane, et al., 2005; Jezewski, et al., 2003; New Zealand Medical Association, 2004). Participants also acknowledged the need for nurses to be sensitive to patients' needs in advance directive communication. Nurses showing sensitivity to the patient enables the patient to consider what is important to them in terms of advanced directives. Remaining sensitive to the patient is an important characteristic required of all health professionals involved in advance directive conversations. The challenge for the health team is to maintain an understanding into the patient's values and ideals (Crane, et al.); at the same time showing sensitivity to family members. Family members are also considered important sources of patients values, and may provide invaluable assistance required for united decision making in advance care planning (Crane, et al.).

Clear effective communication among family members, the patient and health professionals are essential in discussing advance directives (Blondeau, et al., 2000). Findings from my study suggested adequate time must be allowed for advance directive

discussions to ensure that information is shared and is understood by the patient and whānau/family. These findings align with findings from other researchers who emphasise the importance of allowing adequate time for advance directive discussions (Jezewski, et al., 2005; Ramsaroop, et al., 2007). In contrast, one participant believed families were able to make decisions about end-of-life care without advance directives, as long as there was effective communication between the family and health professionals caring for the patient. Although she was not sure about the value of advance directives, this participant's values were consistent with the other participants – that of respecting and caring for the patient. The participants identified the importance of understanding and accepting the patient and their total self. This was illustrated by the nurses' openness to the total self of the patient, making provision for authentic communication and therapeutic relationships. This aligns with Watson's (2006) carative factor five (see Appendix A) in which the acceptance of positive or negative expressions are considered healing practices toward the patient and family. These processes are underpinned by creating authentic and sharing communication processes while remaining in others' frames of reference (Watson, 2006).

Furthermore, participants identified that clear, respectful communication between patients and their families may help identify patient wishes, particularly in times of family conflict or stress. These findings were congruent with Blondeau et al. (2000) who suggested advance directives make patients' expectations clear to family and health professionals, which as a result may avoid future conflict. Through accepting the individuality of each patient and his or her whānau/family nurses may be able to ensure effective communication occurs to avoid the possibility of family conflict.

Thompson et al. (2003) concur with this finding in terms of advance directives being a way of ensuring that patients' wishes are fulfilled should conflict arise.

Respecting the individual

Respecting the uniqueness of patients, their beliefs and those of their family were further contributing factors identified in valuing the person. The presence of humanistic, altruistic values (Watson, 2006) are recognised in this respect. Nurses need an awareness of their own personal beliefs in order to remain objective and not confuse them with patient beliefs. Several participants acknowledged everyone brings different perspectives and interpretations to their understandings; an important reminder for the nurse to obtain a thorough understanding of the patient's perspectives to ensure the patient remains at the centre of care.

People understand their health knowledge primarily from their cultural inheritance, highlighting the importance of nurses being culturally knowledgeable in order to communicate sensitively, appropriately and constructively in advance directive communication (Auer, 2008). It is through these channels respect is afforded to the individual as indicated by the responses of the participants in my study. This is particularly relevant in New Zealand, where nurses working with Māori whānau/family practice according to the principles of The Treaty of Waitangi, requiring nurses to be culturally competent (Wareham, et al., 2005). Cultural competency in New Zealand refers to effective nursing of a person or family from another culture in a manner that is acceptable to the person or family; a principle underpinning the acknowledgment of individuality. However, Crane et al. (2005) suggest the influence of culture on advance directives is not totally understood; this idea is reflected in my findings. Participants

were unsure how culturally appropriate advance directives were for Māori. They acknowledged the importance Māori culture would have on advance directive discussions, highlighting the respect the participants accorded to the indigenous people of New Zealand. This respect was inclusive of all patients illustrating the important value participants placed upon those individuals and their families.

Summary of Findings

Overall I identified three themes as a result of the data analysis conducted for this study. Throughout my analysis, Watson's Theory of Human Caring informed my interpretations as I coded to the propositions and objectives of this study. The three themes included encountering challenges, facilitating patient voice and valuing the person.

The challenges related to advanced directives were identified by the participants. The challenges included a lack of knowledge particularly around legalities. Advance directives, as part of advance care planning in New Zealand appears to be in its infancy as indicated by this lack of knowledge. Further contributing factors to this lack of knowledge was the fact all of the participants registered prior to 2004 at a time when advance directive communication was not at the forefront. This is supported by the fact that the New Zealand Nursing Council has only just released its first statement ever concerning advance directives. Further challenges for primary health nurses in advance directives were identified as a lack of experience in advance directive communication, ethical dilemmas, how and when to introduce advance directives, multifaceted cultural beliefs, attitudes towards death, and clarity of the meaning of advance directives.

Other challenges included a lack of time in an already heavy workload and the question on where sustainable funding would come from to be able to meet the costs of the nurses' time. Unclear guidelines, unclear role delineation and fragmented or complex communication issues across the primary/secondary health sector also appeared to be evident from this study. A lack of resources and inadequate support to have confident involvement in advance directive conversations were also considered challenges that primary health nurses may encounter in approaching in advance directive discussions.

Nurses' personal and professional values and experiences were identified as important in forming positive attitudes to a potential role for primary health nurses in advance directives. All of the participants of this study supported the belief that advance directive communication should sit in primary health and that the primary health nurse has a role to play in this. They presented views on how this could look in primary health suggesting that advance directive communication is a process that needs to be built upon. The participants identified core values of patient advocacy and patient autonomy as part of their role in advance directives.

Underpinning the challenges and paving the way for advance directive communication is the "core" of nursing as identified by Watson (2006). The "core" relates to the caring processes through which nurses connect with their patients; this was illustrated by caring comments that were consistently expressed by all of the participants in this study. The "core" components identified by participants were patient autonomy, holistic care, effective communication, therapeutic relationships, respect and acknowledging individuality. These "core" components reflected the value participants

placed on their patients and their professional colleagues; these components also placed participants in a position to support their practice and/or interdisciplinary team in their role with advance directives. In recognising those key components the participants acknowledged they could provide patient-centred care relevant to the goals, values and needs of the individual. With adequate support and further education, the primary health nurse is in pivotal position to encourage the therapeutic nurse–patient relationships in order to have the caring in-depth discussions essential to any role in advance directives communication.

Reflections

My experience as a novice researcher has taken me on a steep learning journey. After identifying what I wanted to know, I chose a case study methodology and Watson's Theory of Human Caring to inform my research question, my analysis and my interpretation of the participants' responses in this study. It has been for me a humbling experience to be able to identify the caring attitudes that emanated from all of the participants' narrative in my study.

The 13 semi-structured interviews produced a rich amount of data. I was surprised by the amount of personal and sensitive information the participants were willing to share. An unplanned benefit for participants may have been that of a therapeutic experience (LoBiondo-Wood & Haber, 2010). My analysis and interpretation of this case study enabled me to appreciate the depth of meaning of participants' experiences, attitudes and knowledge about advance directives in terms of their practice. I felt compelled to reflect upon the data in a manner that maintained the

dignity in which these participants shared their stories. I also felt compelled to try to illustrate these findings in a fashion that was as true to their descriptions as possible.

I believe the objectives of this study were attained with the findings crystallised in part by the theoretical framework used, that of Watson's Theory of Human Caring. The primary health nurses' knowledge, attitudes and experiences in advance directives were uncovered using Watson's theory as a guide. This enabled me as the researcher to illuminate to the reader the caring altruistic values of the participants involved in this study.

Limitations

As with all research, the findings of this study must be considered in light of its limitations. The findings are limited by the small number of participants used in this study; therefore the findings may not be generalisable to the wider population of primary health nurses. However, despite this limitation I believe this case study offered insight into the phenomena of primary health nurses' role in advanced directives.

Implications for Nursing Practice

The participants of this study exhibited positive attitude towards advance directives in primary health. Many of their responses were consistent with literature from other nurse specialties and were underpinned by caring characteristics so often attributed to nurses. Participants clearly identified that there is a role for the primary health nurse in advance directives and responses indicated they are in readiness for this challenge. Primary health nurses are in a unique position of forming nurse–patient relationships that are built upon trust and positive regard (Hsu, et al., 2008). An

emphasis on patient values and beliefs is integral to advance directive communication and this was recognised as a key requirement for nurses to have advanced directive discussions.

For the most part the participants considered the nurse's role to include the initiation and/or early discussions of advance directives with the patient. For this to be successfully implemented, role clarification, resources, time, education and a suitable environment is required. The need for administrative, medical and nursing support is also considered a prerequisite. In addition, resource personnel – such as nurses who are specialists in their role – are needed for support and guidance for the primary health nurse and the practice team.

The participants emphasised that their role was not only that of supporting the patient but also supporting the medical team in advance directives, recognising that teamwork is imperative to successful implementation of this role. This is determined by the culture of the primary health practice, and by the importance the team places on advance directive communication and team decisions. Tensions may arise as nurses try to balance the already busy workload of the day requiring inbuilt time to carry out this role. This brings into question issues of funding. As many of the general practices where primary health nurses work are businesses and require fees for service, funding for this role needs to be considered.

The importance of health professionals in educating the public to raise an awareness of advance directives was another concept shared by the participants in this study. Primary health organisations could become involved in education and the

promotion of advance directives to raise public awareness. Furthermore, by inviting interdisciplinary and public debate and discussion about advance directives, strategies could be developed that meet the end-of-life needs of the people.

Implications for nursing education

Although there were varied interpretations of what an advance directive is, there were some significant knowledge gaps identified, particularly in relation to the legalities and validity of advance directives. This needs to be remedied at a national level, with education provided at the nursing education level, continuing education level and postgraduate level. Six of the thirteen participants were educated at post graduate level. However, this level of education did not seem to have a significant effect on the participants' knowledge of advance directives. This suggests that advance directives have not been a priority in nursing education in the past.

As most nurses are expected to give care to the dying person (NZNO, 2010), the importance of education at the undergraduate nursing curricula level directed at empowering nurses to participate in ethical decision-making in end-of-life care is paramount. A clearer understanding of ethics and law related to end-of-life care should help nurses make ethically sound decisions in caring for the dying patient. This may reduce professional and patient stress and enhance the patient and family's journey in their end-of-life care. Participants of this study made references to medical personnel or families overriding advance directives, a finding identified in other studies (Jezewski, et al., 2003; Pavlish, et al., 2011). Education at continuing education and postgraduate level may be directed to the various nursing specialty areas in an effort to empower nurses in times of these ethical dilemmas.

Given the multicultural society we live in, nurse educators can incorporate into their curricula courses on cultural competency and end-of-life decision making such as that involved with advanced directives. For example, nurse educators can encourage students to think critically about how best to meet the multifaceted Māori, Pacific Island cultural needs and the needs of other ethnicities in order to practice cultural competency. Further to this, nurse educators need to be versatile in teaching ethics to the multicultural workforce of nurses today. Education on the taboos evident in Western cultural attitudes toward death and dying may give nurses a greater understanding into the effect this may have on the uptake advance directives. Courses on communication that include theories of death and dying may help student nurses uncover their own beliefs and attitudes towards death and the impact this could have on their patient care. Greater awareness of such beliefs can help health professionals' better facilitate successful advance care planning for effective end-of-life care.

Given the complexities involved in initiating advance directives conversations, education aimed at providing primary health nurses with the necessary skills to introduce these types of discussion would give nurses confidence to do so.

Recommendations for Further Research

As with much qualitative research more questions than answers were created. While there was some general knowledge about advance directives among participants, research into developing education programmes about advance directives specifically for primary health nurses is essential to provide primary health nurses with the skills to become involved in advance directive discussions.

Therapeutic nurse–patient relationships and effective communication skills were seen as a key focus area integral to the process of advance directive communication. Research focusing on barriers for nurses in having advance directive discussions may provide direction for nurses to develop the necessary skills to introduce these types of discussions and could inform policy makers.

Advance directives are a multi-disciplinary responsibility requiring various levels of teamwork, integral to advance directive discussions. Therefore, research into inter-professional roles may determine how health professionals could function together in the role of advance directive communication in an effort to best meet the patient's needs. Integrated interdisciplinary teamwork was seen as problematic in this study in providing seamless provision of autonomous end-of-life care. Research focusing on the elements of effective teamwork related to advanced directives could enhance the end-of-life journey for patients as they transition between primary and secondary services.

Research is required to investigate the cultural implications of advanced directives to determine their cultural acceptability and appropriateness in providing end-of-life care for the different cultural groups. This is important to be able to provide both ethical and culturally competent care that as health professionals nurses are bound to provide. In the New Zealand cultural context, further research into the beliefs and attitudes of the public regarding advance directives is required to determine their suitability in that context. Cultural safety and competency are core values of the New Zealand Nursing Council (Te Kaunihera Tapuhi o Aotearoa Nursing Council New Zealand, 2009). To achieve cultural competency in advance directives, research is

required into the needs of Māori in regard to beliefs and appropriateness of advance directive communication to ensure congruency with their cultural needs and Treaty of Waitangi principles. Furthermore, research is needed into Pacific Island population groups living in New Zealand to determine their views in regard to beliefs and appropriateness of advance directives.

Participants also discussed cultural attitudes and taboos towards death and dying. Future research could be conducted on such taboos in the context of advanced directives and the effect this may have on nurses' ability to participate advance directive conversations.

Primary health is only one area where advance directives may sit. There was a paucity of research on advance directives and the role of New Zealand nurses covering all nursing specialities. Therefore, more research into advanced directives in the context of all nursing specialities may contribute to knowledge of the nurses' role in advance directives in the New Zealand context.

Concluding Comments

The overall aim of this study was to determine what role, if any, the primary health nurse plays in advance directives. The objectives were achieved in uncovering and gaining a description of primary health nurses' knowledge, attitudes, and experience in advance directives. The issues surrounding advance directives are complex. Participants in this study identified that primary health nurses in New Zealand have little or no experience in advance directives but recognised their potential for enhancing end-of-life care. Participants believed there was a role for primary health

nurses to play in advance directive discussions. These beliefs were partially attributed to the altruistic and holistic values of the nursing profession in promoting care and healing and respecting patient autonomy. Watson's Theory of Human Caring, used as the theoretical framework in this study, underpinned these findings and illuminated the importance of caring relationships to support these types of conversations.

Many complexities were identified associated with advance directives including when and how to introduce advance directives, multi-layered communication issues, clarity of advance directives and, importantly, the relevance of advance directives to the indigenous people of New Zealand. Cultural considerations to Māori in respecting the Treaty of Waitangi and to the individual Pacific Island groupings need to be addressed.

Although advance directives are designed to provide effective end-of-life care, more research is required to determine their acceptability with other health professionals and the multi-cultural groups of today's society. Advancements in advance directives and advance care planning will then progress in a manner that generates effective and appropriate end-of-life care that is acceptable to patients and their families, at the same time respected by health professionals involved.

This study has been completed at a pivotal point in New Zealand where there is a national drive to investigate and develop advance care planning strategies. Ethical and legal aspects need to be clarified to provide understanding and a way forward for primary health nurses to work with advance directives. Results from this study provide insight into the potential readiness of primary health nurses to move forward and become a part of the national development toward advance care planning for effective

end-of-life care. The participants demonstrated how the “core” values they hold underpin their belief in advance directives in providing effective patient centred end-of-life care. Further education in terms of advance directives, and their ethical and cultural implications, along with adequate support are needed to provide nurses with the skills to become involved in these discussions. These coupled with the ability to establish strong bonds with patients built on trust and positive regard, place primary health nurses in a central role to support the patient in advance directive discussions.

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Glossary of Terms

Advance care planning	the voluntary process of preparing for likely scenarios near the end-of-life. It usually includes assessment of and discussion about a person's understanding of their medical history and condition, values, preferences, and personal and family resources (Ministry of Health and Hospice New Zealand, 2010).
Advanced form	an administration support form for primary health providers to provide referrals and access funding for services from the primary health organisation
Baby boomer	a person born in the years of the baby boom between 1946 and 1964 http://humanresources.about.com/od/glossaryb/g/boomers.htm
Cardiovascular disease clinic	clinics run by primary health nurses to establish what risk a person may have for having a cardiovascular event. Cholesterol, blood sugar levels, weight, smoking, blood pressure and family history are included in the investigation.
Care plus	an initiative as part of the Primary Healthcare Strategy that provides additional funding for Primary Health Organisations (PHOs) to give better care to people who use high levels of care or have high needs because of chronic conditions or terminal illness

Co-morbidities	two or more co-existing medical conditions or disease processes that are additional to another diagnosis
Chronic health management clinic	nurse clinics supported by the Primary Health Organisation to manage patients with chronic conditions with regular reviews to maintain their best possible health
Enduring power of attorney	is a formal document giving someone the power to act for you if you if you lose the capacity to make decisions yourself. There are two types – one for financial and one for personal care and welfare. They may be different people. http://www.communitylaw.org.nz/Welfare-guardian.215.0.html
Euthanasia	the practice of ending the life of an individual suffering from a terminal illness or incurable condition, as by lethal injection or the suspension of extraordinary medical treatment
Get checked diabetes clinic	programme funded by Primary Health Organisations and ensures that every New Zealander with diabetes can have a free annual check-up with their GP or GP practice nurse/primary health nurse
Holistic	care of the entire patient in all aspects
Iwi	extended kinship group, tribe or nation http://www.maoridictionary.co.nz/

Karakia	prayer, grace, blessing http://www.maoridictionary.co.nz/
Koha	gift or offering http://www.maoridictionary.co.nz/
Noa	unrestricted, ordinary, free from tapu http://www.maoridictionary.co.nz/
Pākehā	New Zealander of European descent http://www.maoridictionary.co.nz/
Palliative care pathway	agreement between hospice New Zealand and the Primary Health Organisation to provide free accessible care to patients requiring palliative care
Primary health organisation (PHO)	provides essential primary healthcare services to those people enrolled with the PHO. PHOs bring together doctors, nurses and other health professionals (such as Māori health workers, health promotion workers, dieticians, pharmacists, physiotherapists, psychologists and midwives) in the community to serve the health needs of their enrolled populations
Steiner philosophy	spiritual movement founded by Rudolf Steiner in the early 20 th century
Stroke	sudden death of brain cells in a localised area due to inadequate blood flow
Tapu	sacred, restricted, set apart http://www.maoridictionary.co.nz/
Tikanga	correct practice, custom, lore http://www.maoridictionary.co.nz/

Welfare Guardian

a person appointed by the Family Court to make decisions on behalf of another person who is totally unable to make decisions about their personal care and wellbeing

<http://www.communitylaw.org.nz/Welfare-guardian.215.0.html>

Whānau

family, extended family group

<http://www.maoridictionary.co.nz/>

Appendices

Appendix A: Carative Factors

- 1) Formulation of humanistic–altruistic system of values. Values learned early in life but can be influenced by nurse educators. This may be known as satisfaction through giving and extension of self.
- 2) The installation of faith and hope. This incorporates humanistic and altruistic values thus facilitates holistic nursing care and positive health in the patients. Effective nurse-patient relationships promote wellness by facilitating the patient to use health seeking behaviours.
- 3) Cultivation of sensitivity of one's self and to others. Acceptance of feelings leads to self-actualisation through self-acceptance for the nurse and patient. Nurses are then able to be authentic and genuine to others.
- 4) Establishing a helping–trust relationship. The relationship is essential to trans-personal caring. It involves congruency, warmth and effective communication.
- 5) Promotion and acceptance of expression of feelings, both positive and negative. Sharing feelings can be a risk taking experience for the nurse and patient. The nurse needs to be prepared for both types of expression, and recognise emotional and intellectual understandings of each situation differ.
- 6) Systematic use of scientific problem. This factor recognises that problem solving processes used in nursing are similar to research processes in that they are systematic and organised.
- 7) Promotion of interpersonal teaching–learning. This factor separates caring from curing. It seeks to enable patients to take responsibility for their wellness and health through learning self-care, determining personal needs and opportunities for growth.
- 8) Provision for a supportive, protective and/or corrective mental, physical, socio-cultural and spiritual environment. Nurses must recognise the influence internal factors such as mental and spiritual wellbeing and external factors such as privacy, comfort and clean aesthetic surroundings have on the patient.

- 9) Assistance with gratification of human needs – the nurse recognises the biophysical, psychophysical, psychosocial and intrapersonal needs of self and patient. Patients must tend to lower order needs such as food, elimination and activity before they can achieve higher order needs such as affiliation and self-actualisation.
- 10) Allowance for existential–phenomenological forces. Phenomenology describes data of the immediate situation that gives patients understanding of the phenomena. Allowing for existential and phenomenological forces provides thought provoking exercises facilitating a deeper understanding of self and others (Jesse, 2010).

Appendix B: Caritas Processes

- 1) Practice of loving kindness within the context of caring consciousness.
- 2) Being authentically present thus enabling the belief systems of the patient and the nurse to be sustained.
- 3) Cultivating one's own personal spiritual practices.
- 4) Developing and sustaining helping trusting nurse–patient relationships.
- 5) Being present and acknowledging positive and negative feelings as a connection with the spirit of the nurse and the patient.
- 6) Creative use of self and all ways of knowing to engage in caring-healing practices.
- 7) Engaging in authentic teaching–learning experiences while remaining in the patient's frame of reference.
- 8) Creating a healing environment at all levels, including physical and non-physical levels, to promote wholeness, comfort and peace.
- 9) Assisting with meeting the patient's both lower order and higher order needs, which promote mind/body/spirit wholeness.
- 10) Opening and attending to spiritual and existential dimensions of self and the one being cared for (Jesse, 2010).

Appendix C: Ethical Approval



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington

Phone: (04) 496 2405

Fax: (04) 496 2191

Email: central_ethicscommittee@moh.govt.nz

12 July 2010

Ms Raewyn Davidson
Graduate School of Nursing, Midwifery and Health
Victoria University of Wellington
PO Box 600

Dear Ms Raewyn Davidson

Ethics ref: **CEN/10/EXP/29** (please quote in all correspondence)
Study title: The Role of the Primary Health Nurse In Advance Directives: A New Zealand

This study was given ethical approval by the Central Regional Ethics Committee on 3 July 2010.

Approved Documents

- Appendix A: Research Proposal: Primary Health Nurses/Advance Directives
- Appendix B: Invitation/Information Sheet, Primary Health Nurses/Advance Directives
- Consent Form C: Consent for Interview: Primary Health Nurse/Advance Directives
- Appendix F : Information Sheet Practice Managers: Primary Health Nurses/Advance
- Appendix D: Interview Schedule : Primary Health Nurses/Advance Directives
- Appendix F: Demographics: Primary Health/Advance Directives

This approval is valid until 03/03/2011, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

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

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by 3 July 2011. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Requirements for the Reporting of Serious Adverse Events (SAEs)

For the purposes of the individual reporting of SAEs occurring in this study, the Committee is satisfied that the study's monitoring arrangements are appropriate.

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

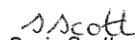
- are *unexpected* because they are not outlined in the investigator's brochure, and
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and
- if the study involves blinding, result in a decision to break the study code.

There is no requirement for the individual reporting to ethics committees of SAEs that do not meet all of these criteria. However, if your study is overseen by a data monitoring committee, copies of its letters of recommendation to the Principal Investigator should be forwarded to the Committee as soon as possible.

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

We wish you all the best with your study.

Yours sincerely


Sonia Scott
Administrator
Central Regional Ethics Committee
Email: sonia_scott@moh.govt.nz

Appendix D: Table 2.1.

Table 2.1.

Personal Contributing Factors to Completing Advance Directives

Personal factors contributing to formulation of advance directives	Source
Not wanting to be a burden on others	Detering, et al., 2010; Thompson & Hastie, 2007; Munday, et al., 2007
Aging	Jezewski & Meeker, 2005; Ramsaroop, Reid, & Adelman, 2007; Wissow et al., 2004
Not wanting to lose control	Detering, et al., 2010; Douglas & Brown, 2002; Duke et al., 2007
A desire to keep off artificial life support	Douglas & Brown, 2002
Declining health	Douglas & Brown, 2002; Duke et al., 2007;
Past experience with dying friends or relatives	Jezewski & Meeker, 2005;
Longer length of time at practice	Ramsaroop, et al., 2007
Comfort with notion of death and dying	Jezewski & Meeker, 2005;
Not wishing to prolong the dying process	Detering et al., 2010

Appendix E: Table 2.2.

Table 2.2.

Personal Barriers to Completing Advance Directives

Personal barriers to completing advance directives	Source
Lack of information about advance directives	Badzek et al., 2006; Douglas & Brown, 2002; Jezewski & Meeker, 2005; LaPorte matzo & Witt Sherman, 2006
Lack of access to advance directive forms	Douglas & Brown, 2002; LaPorte matzo & Witt Sherman, 2006
Inadequate understanding on how to complete or interpret form	Douglas & Brown, 2002; Elliott & Olver, 2003; Jezewski & Meeker, 2005; LaPorte matzo & Witt Sherman, 2006; McCarthy, et al., 2008; Thompson, et al., 2003
Family disagreement on decisions about medical treatment	Douglas & Brown, 2002;
Lack of discussion with physician	Douglas & Brown, 2002; Maxfield, Pohl, & Colling, 2003; McCarthy, et al., 2008
Irrelevance to time of life/Deferring to later	Eliot & Olver, 2003; Jezewski & Meeker, 2005; Ramsaroop, et al., 2007
Anxiety related to discussing death	Badzek, et al., 2006; Jezewski & Meeker, 2005
Social/cultural context in creating meaning around advance directives	Jezewski & Meeker, 2005
Lack of privacy	Ramsaroop, et al., 2007
Deferring to other family members	Ramsaroop, et al., 2007
To distressing to think about	Jezewski & Meeker, 2005; Ramsaroop, et al., 2007
Inconsistent with religious beliefs	Ramsaroop, et al., 2007

Appendix F: NZNO (2010) Mission Statement

The relevant points covered by the NZNO 2010 mission statement surrounding advance directives include:

- a) Nurses must adhere to legislation and uphold ethical standards of nursing practice, thus need to be familiar with the NZNO code of ethics and legislation related to informed decision making and privacy.
- b) Euthanasia and assisted suicide are not legal in New Zealand as part of advance care planning.
- c) Nurses and other health professionals have a legal and ethical duty to respect the individual's wishes.
- d) Good communication between health professional, individuals and whānau/family underpins quality end-of-life care.
- e) A primary function of the nurse is to ensure the individual's and whānau/family wishes are central to discussion – when a shared understanding is unable to be reached the nurse may be required to assist others with how to proceed.
- f) NZNO recognizes a person's right to make informed decisions under the Code of Health and Disability Services Consumers' Rights, 1996.
- g) Nurses may need to inform whānau/family of a dying person's advance directives as long as it is not breaching client/patient confidentiality.
- h) The health team will respect valid advance refusals of treatment and try to interpret statements of client/patients' values and wishes in terms of the possible treatment options.
- i) NZNO supports the right for individuals to refuse treatment – if the nurse is present in signing of advance directives he or she needs to be confident the

individual has adequate information on various healthcare options, understands the directive and is acting voluntarily.

Appendix G: Case Descriptions

Case	Description of area of work
Lesley	Worked in a medium size practice predominantly working with a European population, large numbers of over 65's. Premises were located in a suburban higher socio-demographic area. Physical space is limited for the number of staff. Nurses predominantly work in cubicles with a multipurpose room able to be booked for more private consultations.
Bronwyn	Worked with one other nurse in a small general practice drawing from both a lower and higher socio-demographic area. The population was mixed in ethnicity and age groups.
Rachel Pamela Harriet	These three participants worked in a large general practice located in the city centre. They provided a large range of health services to a large mixed ethnicity and age group population with a number of allied services attached to the practice. Each participant had her own specialty within the practice and afforded rooms as appropriate.
Richard	Worked in a medium sized practice with a higher population of Māori as well as those of European ethnicity. Premises were located in a suburban lower socio-demographic area.
Heather	Worked in a medium size general practice serving a population of mixed ethnicity with high numbers of over 65 year olds. Premises were located in a suburban area drawing from both lower and higher socio-demographic areas. Heather worked as part of a team of nurses supporting general practitioners.
Anita	Worked in a large multipurpose general practice predominantly with a higher socio-demographic population of mixed ethnicity. Premises were located in a suburban area. There was ample physical space for the team of nurses to work either in cubicles or rooms for privacy. Allied services were close to the centre.
Jill	Worked in a large Māori health provider meeting the needs of Māori. Large physical area to work in with privacy available if needed located in a suburban area. There were large numbers of nursing and allied staff supported by general practitioners.
Diane	Worked in a medium sized general practice with a mixed ethnicity and age group population. Practice was situated in suburban medium socio-demographic area. There was a large range of services provided with allied services close by. Nurses worked in cubicles with multipurpose rooms for privacy as needed.

Libby	Worked in a small physical practice but meeting the needs of a large Māori and Pacific population. Works from own designated room. Situated in busy suburban centre drawing from a lower socio-demographic area. Works with one general practitioner but well supported as part of a larger Māori health provider.
Narelle	Worked in a Māori health provider serving the needs of Māori and Pacific people. The physical surroundings were large and multipurpose with the ability for privacy as necessary. Large numbers of multi-disciplinary staff were available. No general practitioners were specifically attached to the service but providers had relationships with the patients' general practitioners. The practice was situated close to the city centre but many mobile services were provided.
Denise	Worked in a medium sized general practice drawing from both lower and higher socio-demographic areas. The population was of mixed ethnicity and age group. Denise worked as part of a larger nursing team leading her own nursing specialty. Allied services were close by.

Appendix H: Consent to Participate in Research



CONSENT TO PARTICIPATE IN RESEARCH

Research Title – The Role of the Primary Health Nurse in Advance Directives: A New Zealand Study

English	I wish to have an interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu	E	Nakai
Sāmoan	Ou te mana'o ia i ai se fa'amatala upu	Ioe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	Io	Ikai
	<i>Other languages to be added following consultation with relevant communities.</i>		

I have read and understood the attached 'Invitation/Information sheet' and I am satisfied that any questions I may have about participating in the interview have been answered.

I have had an opportunity to ask questions and have them answered to my satisfaction.

I agree to participate in this semi-structured interview and understand I may withdraw at any time without explanation and that I do not have to answer all questions.

I understand that I will receive a summary of my interview and will be able to comment and make changes.

I understand that any information provided by me will be unidentifiable and that my name will remain confidential to the researcher.

I understand that the recordings, notes and transcripts of my interview will be kept in a secure place, that no one other than the researcher, her supervisor and transcriptionist will have access to them.

I understand that the tapes will be electronically wiped at the end of the research and the transcripts destroyed after 10 years.

I would like to receive a summary of the research findings when the research is completed.

Yes No

I agree to take part in this research.

Name: _____

Signed: _____

Date: _____

Address for summary or report: _____

Appendix I: Information sheet for Practice Managers



Information sheet for Practice Managers

Introduction

My name is Raewyn Davidson. I am a NZ Registered Nurse who has worked in Primary Health for the past eight years in Napier and is now working full-time on a research study. This research is a requirement of study towards a Masters in Nursing with the Postgraduate School of Nursing and Midwifery, Victoria University, Wellington.

My study involves looking at the nurses' points of view on advance directives in Primary Health. As many people are living to an older age, advance directives are one way to try and improve patient end-of-life care. Literature suggests there is a role for primary health nurses to play in advance directive communication; therefore I believe it is important that the voices of those nurses working in this field are heard on this complex topic.

About the study

In this study I want to find out the knowledge, attitudes, and experiences of primary health nurses in advance directive communication. This has not yet been studied in New Zealand. One senior nurse from each General Practice and Maori Health Provider in Hawke's Bay will be invited to participate. The location for the interviews will be chosen by participants, to be held at a mutually suitable time. While I would welcome talking to a senior nurse from your practice, he/she is under no pressure to take part in the study. It is voluntary for the nurse to participate.

Support for the proposal has been obtained from the Hawke's Bay Primary Health Organisation (HBPHO), the Hawke's Bay District Health Board (HBDHB) and Cranford Hospice. Consultation has occurred with the Maori Liaison Coordinator at the HBPHO and the Maori Health Manager at the HBDHB who have indicated their support and requested the findings be presented on completion of the research.

This is a descriptive study that aims to provide a basis for ongoing research. The research may also be helpful for other health funders and planners. The study will be supervised by Dr Salomé Meyer, Senior Lecturer and Learning & Teaching Advisor, Graduate School of Nursing, Midwifery & Health, Victoria University of Wellington.

What does being involved in the study mean?

A personalized letter of information and invitation will be sent to a senior nurse at your practice. This will be followed with a telephone call to discuss the study and answer any questions he/she may have. Should the nurse consent to inclusion in the study a voluntary consent will need to be signed. I will then arrange to meet with the nurse at a place chosen by him/her at a mutually suitable time and venue. A demographic survey will be completed followed by a semi structured interview. It is expected the interview will last approximately 30–60 minutes. If agreed, I would like to tape the interview to help me recall everything said. I will offer the nurse a copy of the transcription to validate his/her responses. This will be confidential and non-identifiable.

Confidentiality

Everything said to me is confidential and no material that could personally identify the nurse or the workplace will be used in any reports on this study. Audiotapes and transcripts of interviews will be stored in a secure database and a locked filing cabinet accessible only by me. All material will be destroyed after 10 years.

Results

The study will be completed by March 2011. At that time a summary of results from the study will be sent to the participant.

This study has received ethical approval from the Central Regional Ethics Committee. (CEN/10/EXP/29 3 J 2010)

Please feel free to contact the Principal Investigator if you have any questions about this study:

Full names and contact details of Researchers:

Principal Investigator, Raewyn Davidson, RCN, BN: Phone (06) 8353680 or 027 4366074
Email radav@xtra.co.nz

Academic Supervisor: Dr Salomé Meyer, PhD(CIE), MEd(CAE), BCur IetA(Hons)(Adv. NE), BCur IetA(NE), RN. Senior Lecturer and Learning & Teaching Advisor, Graduate School of Nursing, Midwifery & Health, Victoria University of Wellington. PO Box 7625, Newtown 6242, Wellington, New Zealand. Tel: 64 4 463 6150 Fax: 04 463 5442

Email salome.meyer@vuw.ac.nz WWW <http://www.victoria.ac.nz/nmh>

Appendix J: Invitation and Information Sheet for Interview



INVITATION AND INFORMATION SHEET FOR INTERVIEW

Title of study: The role of the Primary Health Nurse in Advance Directives: A New Zealand study.

Dear . . . ,

You are invited to participate in a qualitative study looking at what the perceptions of primary health nurses are on advance directives in Primary Care in New Zealand.

This study will be done as part of a Masters of Nursing degree by Raewyn Davidson and is being supervised by Dr Salomé Meyer, a senior lecturer in the Graduate School of Nursing and Midwifery and Health at Victoria University of Wellington.

This study has been granted ethical approval by the Central Regional Ethics Committee [CEN/10/EXP/29 3 July 2010].

Introduction

Reflecting on the outcome of end-of-life choices, the importance of patient/whānau autonomy, rising costs and consumerism raises the question of the importance of advance directives and how primary health nurses could support this. With the development of the *New Zealand Palliative Care Strategy 2001*, primary health has been designated as having an important role, within the multi-disciplinary team, caring for those at end-of-life (Ministry of Health, 2001). Literature suggests that with an increase in palliative care involvement and an aging population, there is a role for primary health nurse in advance directive communication. As many people are living to an older age, advance directives are one way to try and improve patient/whānau autonomy and improve end-of-life care.

In particular, there is an evident gap in the research literature regarding New Zealand nurses' involvement in advance directives. Therefore, I believe it is important that the voices of those nurses working in this field are heard on this complex topic. In this study I would like to explore the knowledge, attitudes and experiences of nurses working in primary health, relating to advance directives. It is hoped this research study will provide a baseline for future research.

Treaty of Waitangi Obligations

This study will underpin the principles of The Treaty of Waitangi. Consultation has occurred with the Māori Health Manager at the Hawke's Bay District Health Board (HBDHB) and the Māori Co-ordinator at the Hawke's Bay Primary Health Organisation (HBPHO). Both have indicated their support for the study and requested the findings be presented to them on completion of the research. Iwi involvement is encouraged throughout the research to ensure these three principles of protection, participation and partnership are followed. This may include assistance with analysis and/or subsequent dissemination of results.

Ethical Considerations

The research will be undertaken in a way that respects the rights, culture, and privacy of all concerned. Informed consent will be obtained only after a full explanation of the research study has been given. This will include the purpose and validity of the research, what is to be gained from it, who will be involved, the methodology to be used, the projected timeline of the project, what will be expected from the participant and the responsibilities of the researcher. Principles of justice will be followed, ensuring no discrimination in selecting participants. All agreements will be honoured between the researcher and the participant.

The Question

What role do Primary Health Nurses have in Advance Directive communication?

Purpose and Objectives

The purpose of this research is to uncover what knowledge, experience and attitudes primary health nurses have concerning advance directives. It is hoped this will establish what role (if any) primary health nurses currently play in this field in New Zealand and may provide a baseline for future research. The description may also be helpful for other health funders and planners.

The objectives of the study are to:

- Explore and describe the primary health nurses' general knowledge relating to advance directives.
- Describe the primary health nurses' attitudes to advance directives.
- Determine and describe the primary health nurses' experiences with advance directives
- Describe the primary health nurses' involvement with advance directives in primary health

What is involved?

This research study is a descriptive, qualitative study that uses a semi-structured interview schedule. You will be interviewed by me, the principal investigator.

There will be a written demographic questionnaire, which I would like to give you to fill out at the beginning of the interview. This will be confidential and non-identifiable.

Attached are a voluntary consent form and a self-addressed envelope. I will telephone you within the next week to discuss the study and answer any questions you may have. If you are happy to take part in the research, please return the signed consent form to myself by **DATE**. Your participation in this research is *voluntary*. If you are interested I will contact you again and we will arrange a mutually suitable time and venue to meet. The interview will last approximately 30 to 60 minutes.

You may withdraw from the study at any time without explanation. You do not have to answer all of the questions. This will in no way have any impact on your current or future employment.

No material that could personally identify you will be used in any written reports on this study.

During the interview you will be asked several semi-structured questions regarding the knowledge, attitudes and experiences of primary health nurses in the involvement or potential involvement in advance directive communication. Everyone who consents to the interview will be offered information about the study.

If you agree, I would like to tape the interview to help me recall everything said. This will be completed by a digital recording device, which will be transcribed by the principal researcher. However, if there is a lot of data, a professional transcriptionist may be employed to assist with this. A signed confidentiality form will be obtained from the transcriptionist.

All of the raw data collected will be stored in locked cabinet or as password-protected electronic documents and will be destroyed 10 years after the completion of this study.

If you have any personal issues that are raised during the interview process, an opportunity will be available for you to discuss these issues confidentially with the principal researcher after interview is completed.

To ensure internal validity of this research, member validation will be used. This will involve sending the transcribed data from the interview back to you to ensure accuracy of the content. If you agree, I could also telephone you to clarify any information/data I may have misinterpreted.

Once the results are formally published these will be offered to you in electronic form and will also be presented to the HBDHB, HBPHO and Cranford Hospice.

Thank you for considering this proposal. Please feel free to contact the principal researcher or the research supervisor if you have any further questions about this study. Alternatively, if you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact the Health and Disability Commissioner at 0800 112 233.

Principal Investigator:

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Reference

Ministry of Health (2001). *The New Zealand palliative care strategy*.
[http://www.moh.govt.nz/moh.nsf/0/65C53A08E9801444CC256E62000AAD80/\\$File/palliativecarestrategy.pdf](http://www.moh.govt.nz/moh.nsf/0/65C53A08E9801444CC256E62000AAD80/$File/palliativecarestrategy.pdf) Accessed 10 September, 2009.

Appendix K: Demographic Survey

1. What is your nursing qualification?

- ☐ Nurse Practitioner
- ☐ Registered Midwife
- ☐ Registered General Nurse
- ☐ Registered Comprehensive Nurse
- ☐ Enrolled Nurse

2. What year did you receive your registration? _____(year)

3. What is your sex?

- ☐ Female
- ☐ Male

4. With which ethnic group or groups do you belong to?

- ☐ New Zealand European
- ☐ New Zealand Māori
- ☐ Samoan
- ☐ Cook Island Māori
- ☐ Tongan
- ☐ Other (please specify) _____

5. What is your age?

- ☐ 20–29 years
- ☐ 30–39 years
- ☐ 40–49 years
- ☐ 50–59 years
- ☐ 60 + years

6. What is your location of work?

- ☐ Napier
- ☐ Hastings
- ☐ Wairoa
- ☐ Waipukurau

7. How many years have you worked as a registered nurse?

- ☐ < 1 year
- ☐ 1–5 years
- ☐ 6–10 years

☐ 11–15 years

☐ 16 + years

8. How many years have you worked as a registered nurse in primary health?

☐ < 1 year

☐ 1–5 years

☐ 6–10 years

☐ 11–15 years

☐ 16 + years

9. What area do you currently practice in?

☐ General Practice

☐ Māori Health

☐ Pacific Health

10. What are your current hours worked per week?

☐ < 20 hours

☐ 20–40 hours

☐ > 40 hours

11. What is your educational qualification?

☐ Certificate

☐ Diploma

☐ Degree

☐ Postgraduate Certificate

☐ Postgraduate Diploma

☐ Masters in Nursing

☐ Other _____

12. What is your religion?

☐ Protestant

☐ Catholic

☐ Jehovah's Witness

☐ Other _____

13. Have you received any formal education about advance directives in your current position?

☐ Yes

☐ No

Appendix L: Demographics Table

Participant number	Nursing Qualification	M/F	Ethnicity	Age group – years	Years as registered nurse	Years worked in primary health	Works in general practice/ Māori health provider	Educational qualification	Religion	Formal education on advance directives
Lesley	RGN	F	NZ European	50–59	16+	6–10	GP	Masters		No
Bronwyn	RGN	F	NZ European	50–59	16+	1–5	GP	Diploma	Protestant	No
Rachel	RCN	F	NZ European	40–49	11–15	6–10	GP	Degree	Catholic	No
Richard	RGN	M	English	60 +	16+	1–5	GP	Degree		No
Heather	RGN	F	NZ European	50–59	16+	16+	GP	Other/ Hospital qual.	Protestant	No
Anita	RCN	F	NZ European	50–59	16+	16+	GP	Degree	Protestant	No
Jill	RGN	F	NZ European	50–59	16+	16+	GP & MH	Postgraduate Diploma	Christian	No
Harriet	RGN	F	NZ European	40–49	16+	16+	GP	Masters	None	Yes
Denise	RCN	F	NZ European/Māori	40–49	16+	11–15	GP	Diploma	Catholic	No
Narelle	RCN	F	NZ Māori	40–49	6–10	6–10	MH	Postgraduate Diploma	Christian	No
Pamela	RGN	F	NZ Māori	60+	16+	1–5	GP & MH	Degree	Mormon	No
Diane	RGN	F	NZ European	50–59	16+	1–5	GP	Masters	Catholic	No
Libby	RCN	F	Pākehā	40–49	6–10	1–5	MH	Postgraduate Certificate	Atheist	No

Code RCN = Registered Comprehensive Nurse

GP = General practice

RGN = Registered General Nurse

MH= Māori Health Provider

Appendix M: Confidentiality Form – Transcriptionist



Confidentiality Form for Transcriptionist.

Masters Research Project

The role of the Primary Health Nurse in Advance Directives: A New Zealand study.

1. I have been provided audio-tapes of interviews for the Masters Research Project of Raewyn Davidson.
2. I understand that confidentiality will be carefully maintained.
3. I understand that all audio tapes and the transcript produced will be identified by an assigned reference number.
4. I understand that the identifying references to names and places in the audio tapes shall not be included in the transcripts.
5. I undertake to maintain confidentiality of the transcripts from audio tapes for this project.
6. I will return all transcripts and audio tapes to the principal investigator.

I _____ (**full name**) hereby agree to maintain confidentiality of transcripts and audio tapes for this project.

Date

Signature

Full names and contact details of Researchers:

Principal Investigator, Raewyn Davidson, RCN, BN: Phone (06) 8353680 or 027 4366074

Academic Supervisor: Dr Salomé Meyer, PhD(CIE), MEd(CAE), BCur

IetA(Hons)(Adv. NE), BCur IetA(NE), RN. Senior Lecturer and Learning & Teaching

Advisor, Graduate School of Nursing, Midwifery & Health, Victoria University of

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Email salome.meyer@vuw.ac.nz WWW <http://www.victoria.ac.nz/nmh>

Project explained by

Project role

Signature

Date

Notes:

1. A copy of the confidentiality form to be retained by transcriptionist and the principal researcher

Appendix N: Confirmation of Themes Checklist



Section A

Name

Address

Dear *participant's name*

Re: “What role, if any, does the primary health nurse have in advance directive communication?”

Thank you for taking part in the above research. I appreciated meeting you for your interview in September 2010. I have collected all of the information required and analysed all of the transcripts. To ensure the research is reflective of the interview content, I am forwarding a number of transcripts with a brief analysis of my interpretation and the themes of the interviews for which I would be grateful if you could confirm or alter should you wish to make any changes.

Overall you consider:

- Advance directives refer to the ability to make decisions around future health preferences should you become incapacitated and unable to make decisions
- The validity and legalities of advance directives can be ambiguous
- Advance directives is largely about autonomy and is part of holistic care
- Advance directives may be overridden by the medical team
- Advance directives would require regular updating
- Advance directives support sensible decision making along with the care and dignity of the client/patient
- Care needs to be taken around advance directives to try and interpret it from the client/patient perspective
- Advance directives fit with your values
- Advance directives fit well into primary health with a team mandate and approach best used.

- Public awareness of advance directives needs to be raised prior to rolling out an identified process
- Advance directive communication is a process best conducted over a number of visits
- Longitudinal trusting relationships are important to advance directive communication
- Barriers to advance directive communication include timing, funding, attitudes and environment
- Maori and Pacific cultural requirements need to be identified around advance directives and suitability determined
- Nurses need education, team support, resources and administration support
- Advance directive communication may add to personal understandings of each other and our communities.

If you would like to provide any further comments, please do not hesitate to do so in the stamped addressed envelope provided by the end of January 2011. If you find it easier, please call me on 8353680.

The information you provided is valuable and will be presented in a thesis hopefully by March 2011. Thank you again for assisting me with this research.

Kind regards,

Raewyn Davidson (Principal Investigator)



Section B

CONFIRMATION OF THEMES CHECK LIST

Masters Research Project

The Primary Healthcare Nurse's knowledge, attitudes, experiences and needs for advance directives in Primary Health.

Name:

I **agree** with the themes listed in the letter provided **Tick**

I **disagree** with the themes listed in the letter provided **Tick**

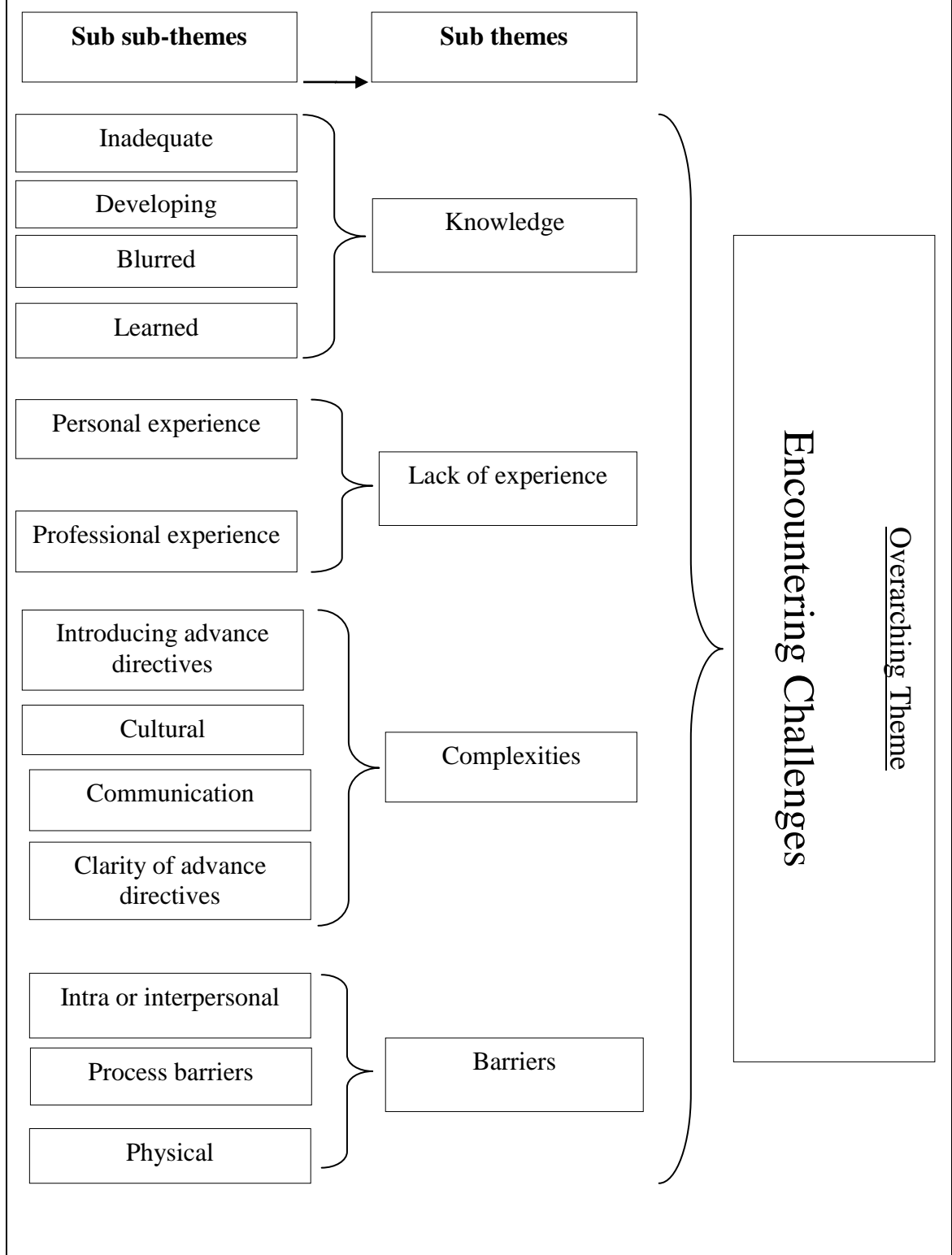
I would like to make additional comments here:

Please return this in the stamped addressed envelope provided.

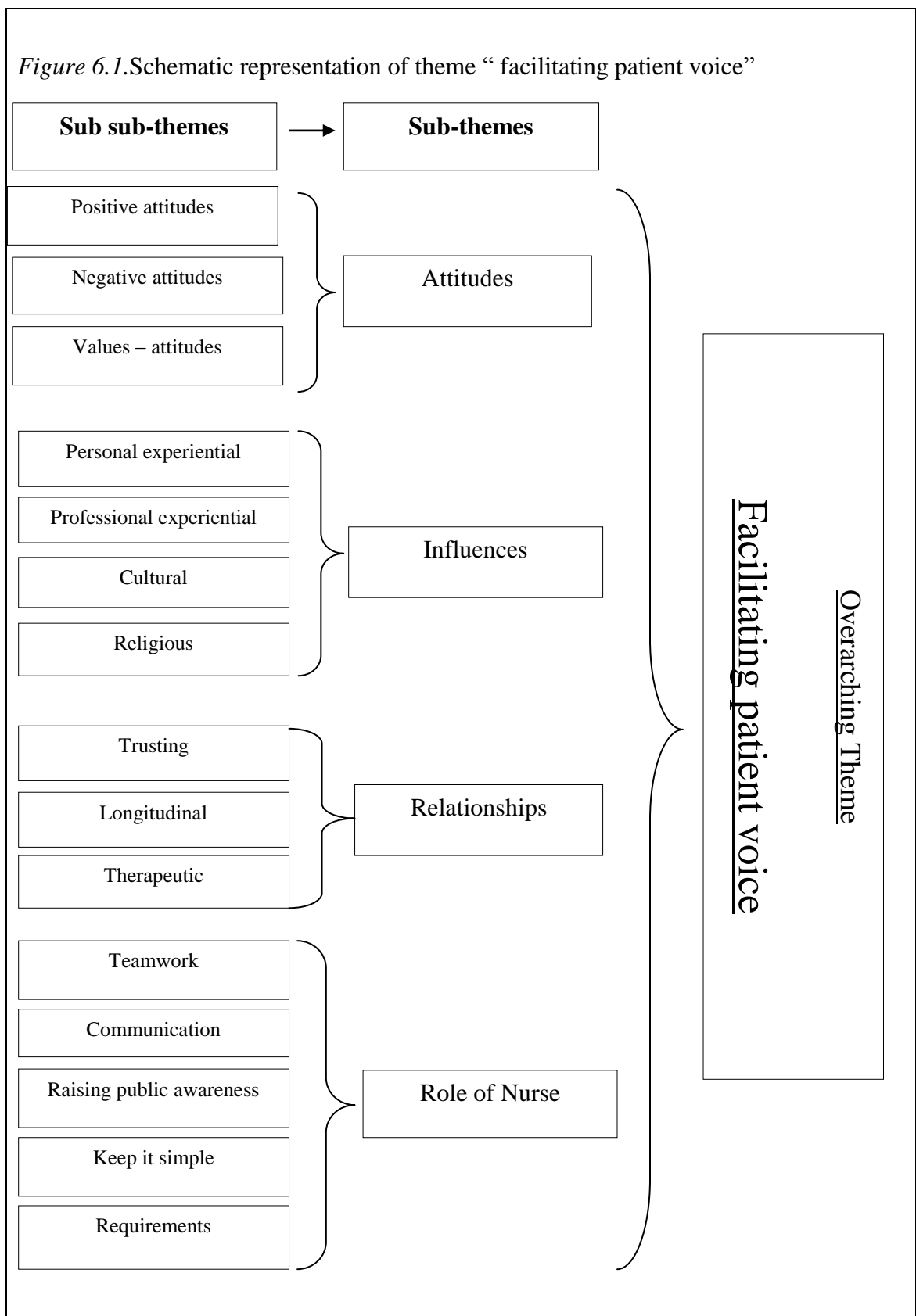
Thank you for your time.

Appendix O: Figure 5.1. Encountering Challenges

Figure 5.1. Schematic representation of theme “encountering challenges”



Appendix P: Figure 6.1. Facilitating patient Voice



Appendix Q: Figure 7.1. Valuing the Person

Figure 7.1. Schematic representation of “valuing the person”

