



## PRIMARY HEALTHCARE NZ NURSES' EXPERIENCES OF ADVANCE DIRECTIVES: UNDERSTANDING THEIR POTENTIAL ROLE

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### Abstract

Advance directives are one aspect of advance care planning designed to improve end of life care. The New Zealand Nurses Organisation released their first mission statement in 2010 concerning advance directives suggesting an increase in the use of these. A burgeoning older population, expected to rise over the next few years, places the primary healthcare nurse in a pivotal role to address the challenges in constructing advance directives. While literature supports the role for primary healthcare nurses in promoting advance directives, no research was found on this role in the New Zealand context. This paper presents results of a qualitative study conducted in New Zealand with 13 senior primary healthcare nurses with respect to their knowledge, attitudes, and experiences of advance directives. Results of the analysis revealed a dynamic process involving participants coming to understand their potential role in this area. This process included reflection on personal experience with advance directives; values and ethics related to end of life issues; and professional actions.

**Keywords:** advance directives; advance care planning; primary healthcare nurses' experience, professional action.

### Introduction

Most nurses can expect to care for dying patients at some stage of their career (New Zealand Nurses Organisation (NZNO) 2010a). A burgeoning older population in New Zealand, expected to rise in the next 15 years (Ministry of Health (MOH), 2002), will impact on healthcare services (MOH, 2006). The vision for primary health services emphasises population health care and a wider range of services such as health promotion, preventative care and co-ordination across services (MOH, 2001a). Within this context, primary healthcare nurses have an important role in providing patient-centred end of life care (MOH, 2001b). In particular, primary health care nurses need to be familiar with patient and whānau/family wishes including those concerning advance

care planning. Advance care planning is recognised internationally as pivotal to providing quality end of life care (Phillips et al., 2011). It offers opportunities for individuals to co-create with significant others and health professionals, their healthcare wishes should they lose their decision making ability (Blackford & Street, 2011).

This study was undertaken to uncover primary healthcare nurses' knowledge, experience and attitudes concerning their role in advance directives. In terms of terminology within the New Zealand context, an

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advance care plan may be considered an advance directive or may be aligned with other existing advance directives and be legally binding (MOH, 2011). In this paper both terms are used interchangeably. An advance directive may be written or oral (Crane, Wittink, & Doukas, 2005; Malpas, 2011).

## Background

In 2010, the New Zealand Nurses' Organisation released their first position statement about the use of advance directives, including nurses' professional and legal obligations regarding informed decision making and advance care planning (NZNO, 2010a). Advance directives align with the New Zealand Nursing Council's nursing competencies and patients' rights to self-determination to refuse treatment and the right to choose (Nursing Council of NZ (NCNZ), 2007).

Traditionally, advance directives, such as living wills and surrogate appointments created by legislative provisions, 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). A more recent approach to advance directives involves co-creating a plan specific to patients' values, relationships, culture and medical condition (Hickman, et al., 2005).

Primary healthcare is aimed at developing self-reliance and determination, and is the first level of contact individuals, families and community have with national health (World Health Organisation, 2001). Although end of life care is provided in a number of settings, some researchers suggest that advance directives in primary care settings be developed while the patient is well or in early disease (Conroy, Fade, Fraser, & Schiff, 2009; Putman-Casdorph, Drenning, Richards, & Messenger, 2009). Despite the large interface primary healthcare has with the public and potential for primary healthcare nurses to facilitate advance directives (Newton, Clark,

& Ahlquist, 2009; Conroy, et al., 2009), a paucity of literature exists about this facilitator role.

## Research Design and Methodology

The purpose of this study was to capture senior primary healthcare nurses' understanding of their role concerning advance directives in New Zealand. A descriptive exploratory research design was employed. This research approach presents the phenomenon under investigation in everyday language (Sandelowski, 2000). Qualitative descriptive studies provide an extensive summary of an event in "everyday terms of those events" (Sandelowski, p. 326).

## Methods

Prior to ethics approval being obtained for the study, recommendations for engaging in Māori research were followed. A consultation process took place with the Māori Health Manager at the local District Health Board (DHB) and the Māori health co-ordinator at the local primary health organisation (PHO). The local DHB human research ethics committee reviewed and approved the study. Written informed consent was obtained from each participant prior to data collection.

Purposive sampling was employed for participant recruitment. Selection criteria included: English speaking, senior primary healthcare registered nurses (over five years' experience as a registered nurse) who worked in general practice, or worked with a Māori health provider for 12 months or more. A list of all general practices in the designated region was obtained from the local primary health organisation (PHO). A letter of invitation was sent to each nurse manager and most senior nurses at each practice site. All New Zealand research is deemed important to Māori (Hudson, Milne, Reynolds, Russell, & Smith, 2010), with the Treaty of Waitangi principles of partnership, participation and



protection embedded within the New Zealand Nursing Council guidelines (NCNZ, 2007). Senior staff from the DHB and PHO assisted in identifying appropriate individuals to help access senior primary healthcare nurses who were Māori or worked in a Māori health provider's practice. Thirty-four primary healthcare nurses were invited to participate in the study; 13 agreed to participate.

All members of the participant group were over 40 years of age and included twelve females and one male, ten of whom were Caucasian, one European/Māori and two Māori. The perspectives of the Māori participants are addressed in another paper (forthcoming). Most participants had over 16 years' experience as registered nurses. With respect to level of education, three had a master's degree in nursing, two a postgraduate nursing diploma, one a postgraduate certificate, four a bachelor's degree in nursing and one a diploma in nursing.

Semi-structured audio-recorded interviews were conducted. The interviews were of approximately 45 minutes duration. Interview questions focused on participants' understanding of advance directives. Each interview was transcribed by a professional transcriber who signed a confidentiality agreement. Confidentiality and anonymity were adhered to, including the use of pseudonyms on all transcribed data and written reports.

A general inductive approach was used for data analysis (Sandelowski, 2000; Thomas, 2006). Inductive analysis involves reading and re-reading textual data to identify an initial list of categories that reflect the substantive content of the interviews. Emerging themes are developed through an iterative process of reviewing the categories, clustering categories into those that are similar and those that are different and identifying patterns. Participants were invited to review the findings; two responded and confirmed that the findings fit with their perspective of the phenomenon of inquiry.

## Findings

In this section we present the findings from our analysis of primary health nurses' perception of their role in advance directives (Davidson, 2011). Two propositions informed the analysis: (a) primary health nurses currently do not have a role in advance directives; and (b) primary health nurses believe that advance directives can promote effective end-of-life care. Advance care planning has gained momentum in New Zealand; for that reason a greater understanding of the primary health nurses' role is required to further advancements in this field. The interview questions led participants to reflect on the subject of advance directives. Most participants had little professional experience with advance directives. However, reflection on personal experience contributed to an understanding of their potential role with advance directives in primary care.

The analysis of the interviews provided an understanding of primary healthcare nurses' perceptions of their potential role with respect to advance directives. Participants described a dynamic process of coming to understand this role, which included: reflection on personal experience with advance directives; values and ethics related to end of life issues; and professional actions that they would take when faced with addressing future wishes of patients.

Participants had limited or no professional experience with advance directives and often prefaced their discussion with words such as, "*I think ...*"; "*From my understanding ...*" or "*I assume that ...*". Only one participant had any direct experience with advance directives in a primary care environment. Although it was 'difficult to broach' this sensitive subject ("*It was extremely difficult to broach the subject ... she had to be in the right space*"), this experience led to establishing an advance directive policy within the workplace.



## Personal experience with advance directives

Nurses' own personal experience with advance directives was central to understanding their potential role in this area. Such experiences included: 1) their wishes regarding their own end of life care options, and 2) choices and decisions they had made regarding care for a close family member who had died. Most participants had considered their own end of life options: "When you start pondering it [advance directives], you realise that actually a middle-aged woman could have a stroke anytime ... it's good to even start thinking about it." Caring for a close family member who was dying influenced participants' perspective of advance directives:

*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 that was quite distressing, as a daughter and granddaughter.*

It is possible such end of life medical interventions would have been different had these family members' choices been supported by an advance directive.

## Values and ethics related to advance directives

Participants' beliefs and values influenced how they viewed their role in operationalising an advance directive or not. That primary care nurses articulate their position about the use of advance directives was highlighted:

*Well, your own personal beliefs, of course – spiritual, ethical, moral. All those things are always going to be in play, and your experience over life ... so it's probably wise for the nurse, if she really feels strongly either way [for or against the use of advance directives], to make that known to her peers, or to whomever ... that maybe it's someone*

*else, another nurse, needs to come and do that work.*

One participant experienced tension between the ethical dilemma of desiring a patient to die with dignity and of acknowledging that more time living could benefit families facing bereavement:

*Just seeing what he went through ... in his mid-seventies it's relatively young. His wife was put through months and months and months of hell. He didn't have quality of life. And ... although, you know, on the other side of that is, I suppose, it gave the family time to say goodbye.*

Most participants were in favour of advance directives. They discussed the role of enabling patients to maintain a "voice when they don't have a physical voice anymore." Their values reflected experiences of caring for dying patients, particularly concerning the quality of the dying, for both the patient and their loved ones. Some participants had witnessed futile interventions during the dying process and had, "seen too many people resuscitated that shouldn't have been ...." Others had witnessed or knew of advance directives being overridden by medical personnel: "I've seen someone resuscitated now twice, when it was made clear to the doctor that they were not to be resuscitated. . . in one case, it was even written." These examples demonstrate a sense of powerlessness experienced by the nurses when patients' autonomy, rights and values are not respected. Participants believed that choice involved a patient's right to change their mind or make decisions that enable them to, ". . . have a bit more control over it [end of life]." It appeared that core values such as dignity, respect, and patient autonomy guided participants' beliefs in ethical nursing practice: "It's about that dignity and that respect and that caring".



## Professional actions and advance directives

All participants asserted that the primary healthcare environment is an appropriate place for discussions about advance directives. Such environments are conducive to building trust and rapport with patients and families – needed for such sensitive discussions. This also involved correct timing in initiating such discussions such as when a person was close to dying:

*It wasn't easy to broach the subject, but I think she was at the stage ... and when she said, "I don't think I'm going to be around for much longer", we took that cue, and said, "Well OK then, where are we going, and what are we doing? And what would be your wishes? And can we have that chat?"*

Participants noted that these conversations were difficult for primary healthcare nurses and for all members of the healthcare team:

*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 [laugh]. It wouldn't be for the faint-hearted too because I don't think even the doctors approach that topic successfully.*

Teamwork was seen as a central part of primary healthcare nurses' role in advance directive discussions and in providing patient-centred end of life care.

The importance of developing therapeutic relationships with patients and their families was central to discussions about advance directives: *"This 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 easy."* Participants believed that creating an advance directive should be a process, not a 'one off' document, drawn up during one interview: *"It's something that ... you would build on. Next time you see them, you might*

*ask for feedback ... have they had a discussion with people they care about?"*

Overall the findings revealed minimal experience with, and limited knowledge of advance directives for this group. Personal and professional experiences within their practice informed their knowledge, as did a belief and need to honour patients' dignity in dying. Nevertheless, participants' experienced tension between patients' desire for a dignified death and medical interventions to prolong life. The entire participant group believed that advance directives enabled patients to have a "voice" and that involvement in advance care planning was part of their professional obligation. The ability to develop therapeutic relationships with patients and their families was a central part of this obligation; such relationships enabled authentic in-depth discussions about an advance directive. Participants believed that primary healthcare nurses are well positioned to engage in such sensitive conversations.

## Discussion

### Personal experience with advance directives

Despite advance directives being a health term in New Zealand since the 1990s, some participants were unfamiliar with the terminology. Participants expressed gaps in knowledge about legislation concerning advance directives, and were uncertain about how to proceed with developing and implementing them. This knowledge gap concurs with findings from other nursing studies concerning advance directives (Duke & Thompson, 2007; Putman-Casdorph, et al., 2009).

Participants' personal experiences particularly with death of a family member or patient influenced their views of advance directives. Their attitudes toward advance directives were positive, supporting findings of other researchers (Duke & Thompson, 2007; Seymour,



Almack & Kennedy, 2010) who found that personal family experience positively influenced community nurses desire to engage in advance care planning discussions.

### **Values and ethics concerning advance directives**

Duke, Yarbrough and Pang (2009) suggest that health professionals may experience moral distress as a result of failure to honour an advance directive. This brings into question the role of patient autonomy in terms of respecting patient choice, an important part of holistic nursing care. Autonomy is a core value underpinning nursing ethics (NZNO, 2010b); participants' belief in autonomy, patient rights and patient advocacy guided their beliefs and experiences with advance directives.

Participants experienced tension between supporting dying with dignity and prolonging life. In addition, they had witnessed what they believed was the futile treatment of dying patients in a health system that was "too medicalised." Pavlish, Brown-Saltzman, Hersh, Shirk and Nudelman (2011) concurred with this form of moral distress in their study on nurses' descriptions of ethically difficult situations. Their findings suggest most ethical issues for nurses relate to end of life care. These issues focused primarily on patients' suffering unnecessarily, due to futile medical interventions and witnessing a patient's advance directive being overridden.

### **Professional actions and advance directives**

Effective communication tailored to the needs of the patient was evident throughout this study. Participants highlighted the need to establish trust and rapport with patients in order to facilitate discussions about advance directives. Results of many studies agree that trust and rapport are integral to advance directive discussions (for example, Munday, Dale, & Murray, 2007; Ramachandran, 2008; Reed, 2011). The primary care environment is seen to be an appropriate setting for engaging in such discussions (Conroy et al., 2009; Maxfield, Pohl & Colling, 2003; Westley & Briggs, 2004). Participants acknowledged the importance of involving the physician and the need to

liaise as a team to successfully integrate advance directive discussions into their role. This finding supports results of other research on advance care planning (Minto & Strickland, 2011; Ritchie, 2011; Woytkiw, 2010).

In order to promote patient engagement with the health professional concerning advance directives, participants identified that nurses be aware of their beliefs. According to Moore (2005) awareness of one's emotions, responses and comfort levels with grief and death is needed in order to maintain authenticity; such awareness impacts nurses' engagement with patients, families and other health professionals.

Participants also believed advance directives could be achieved through a process of ongoing discussions rather than creating a document drawn up at one interview; this would offer patients and their family time to review the information. This finding is well supported in the literature (Auer, 2008; Hickman et al., 2005; NZMA, 2004). Programmes proven to be successful, such as "Preferred Priorities of Care" (Reed, 2011) and "Let Me Talk" (Chan & Pang, 2010) can help engage patients and their families in advance care planning (Maxfield et al., 2003).

### **Implications for primary healthcare nursing practice**

Primary healthcare nurses are well suited to facilitate initiation of advance directives because of their unique relationships with patients and families. The findings of this study support the need for open communication about advance directives in the primary healthcare setting. For this to occur, nurses need to have a sound knowledge of their own personal values and the complexities and legalities around advance directives. They are then in a better position to work with patients and their families to broach the sensitive topic of advance directives. Use of open-ended questions such as, "What is your understanding of an advance directive?", and follow up questions regarding personal preferences would convey respect for patient choice.



Primary healthcare nurses also can take a leadership role in educating other members of health care team about advance directives. This can include communication training and support. Other members of the healthcare team can be engaged in creating protocols for clear recording of advance directive discussions with patients and their families. Primary healthcare nurses can also show leadership with educating the public about advance directives; for example, participation in public forums to discuss advance directives and their use.

## Conclusion

The results of this study suggest that an awareness of one's beliefs and values is integral to engaging in advance directive discussions. Effective communication skills were essential to conversations about end of life issues

including the development of an advance directive. As the range of population-focused services extends in primary healthcare in New Zealand, primary healthcare nurses, with both generalist and advanced skills, will be required to meet the needs of the projected growth in the older population. To meet the challenges of facilitating advance directives and advance care planning an in-depth understanding and clarification of law, ethics and communication strategies is essential. Research on primary healthcare nurses' experiences and attitudes concerning advance directives has not previously been conducted in New Zealand. Given the national drive to implement advance care planning in New Zealand results from this study provide insight into the necessity and also the challenges for primary healthcare nurses in taking forward initiatives on advance directives for New Zealanders.

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