A pilot study of spirituality and spiritual care in Dunedin's residential aged care sector:

interviews with staff

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Contents

> *Spiritual care should be an essential part of comprehensive residential aged care, but is probably the least understood and most often neglected aspect of care.* (Cobb, 2001)

1 Introduction

The New Zealand *Health of Older People Strategy* (Ministry of Health, 2002) requires service providers and health professionals to take a holistic approach to the care and support of the elderly, "including consideration of physical, mental health, social, emotional and *spiritual needs* of older people" (emphasis added). Addressing patients' spirituality positively impacts on a number of health-related outcomes including quality of life and the search for meaning (MacKinlay, 2006). In aged residential care, acknowledging residents' spirituality and facilitating appropriate spiritual care is particularly important to assist residents with the psychosocial tasks of ageing (Moberg, 2001).

We conducted a qualitative pilot study among aged residential care staff working in Dunedin, in which we asked participants about their beliefs relating to spirituality and spiritual care, and experiences of offering or delivering spiritual care to residents. We aimed to answer the following questions:

- How do staff understand spirituality and spiritual care?
- How is spiritual care offered/delivered to residents?
- What are the barriers to delivering spiritual care?
- What are possible improvements to delivering spiritual care?

This report begins by discussing various definitions of spirituality, spiritual care, and models of spiritual care delivery, before briefly reviewing the literature relating to spirituality and aged care. The methods used in this pilot study are described before the qualitative results are presented. Lastly, we discuss the key findings of this study, and compare our results to some of the models of spiritual care delivery discussed in the literature review.

1.1 Definitions of spirituality

As Rumbold (2006) noted, definitions of spirituality exist on a continuum, from the framing of spirituality as a "calling" or relationship with God or a higher power, to understandings emphasising individualism, one's unique identity, and personal achievement. MacKinlay (2001) defines spirituality as:

> *That which lies at the core of each person's being, an essential dimension which brings meaning to life. Constituted not only by religious practices, but understood more broadly, as relationship with God, however God or ultimate meaning is perceived by the person, and in relationship with other people.*

Egan et al. (2011) offer the following definition:

> *Spirituality means different things to different people. It may include (a search for): one's ultimate beliefs and values; a sense of meaning and purpose in life; a sense of connectedness; identity and awareness; and for some people, religion. It may be understood at an individual or population level.*

In common to both definitions is the idea that religious beliefs are but one possible expression of spirituality (MacKinley & Trevitt 2007). This is important in New Zealand where less than 20% of the population are actively religious (Glendall 2009), yet many more consider themselves spiritual or want spiritual care at the end of their lives (Egan 2010).

1.2 Definitions of spiritual care

Like spirituality, a variety of definitions of spiritual care have been proposed. The National Health Service of Scotland (2002) makes a clear distinction between religious care and spiritual care:

> *Religious care is given in the context of the shared religious beliefs, values, liturgies and lifestyle of a faith community. Spiritual care is usually given in a one-to-one relationship, is completely person-centred*

> *and makes no assumptions about personal conviction or life orientation.*

The definition proposed by the National Institute for Clinical Excellence (2004) acknowledges areas of overlap between religious and spiritual care:

> *Spiritual care should not be viewed solely in terms of the facilitation of appropriate ritual, which has implications for the assessment of spiritual needs. The nature of support needed can range from an informal sharing of ideas about the ultimate purpose of existence to the provision of a formalised religious ritual. The appropriate means of meeting need will vary by location, resources and skills available, and the nature of needs assessed.*

In contrast, Manitoba's Central Regional Health Authority (2007) makes no mention of religious care:

> *Spiritual care addresses the ultimate concerns of the whole person, encourages healing through the nurturing of spirituality within the context of the person's beliefs and values as an interdependent component of holistic care.*

These definitions emphasise the intensive, individual, person-centred nature of spiritual care, while the National Institute of Clinical Excellence definition explicitly conceptualises spiritual care as a continuum extending from formal ritual to informal sharing.

1.3 Delivering spiritual care

How spiritual care should be delivered has also been the subject of much discussion. Winslow and Wehtje-Winslow (2007) described five ethical principles of spiritual care which included understanding each patient's spirituality, following the patient's wishes, not imposing spiritual care, understanding one's own spirituality, and proceeding with integrity. These principles highlight the importance of achieving a balance between patient-

centred care on the one hand, and safe practice for the practitioner on the other. Complementing these ethical principles, Cooper et al. (2010) suggested a number of personal characteristics needed to offer quality spiritual care, including a non-judgemental attitude, reflexivity, and tolerance for ambiguity and sadness. The focus of these authors is the personal competence of practitioners.

In contrast, the Consensus Conference (Puchalski et al., 2009) proposed five operational principles: spiritual assessment, spiritual care models and treatment plans, inter-professional team training, continuous quality improvement, and personal and professional development. The success of these principles would be supported by the broad knowledge and skill competencies recommended by Cooper et al. (2010), which include knowledge about bioethical decision making frameworks, family dynamics theory, team work and team building, and teaching and learning strategies. This understanding of spiritual care delivery focuses on organisational competence and measureable managerial outcomes.

Blending the personal and organisational competency perspectives, Gordon and Mitchell (2004) have proposed five general competencies, including an appropriate understanding of the concept of spirituality; awareness of one's own spirituality; recognition of personal limits; knowing when to refer a patient or family members on; and documenting perceived needs, referrals, and interventions. This model also describes tiers of professional competence for staff and volunteers who have different levels of contact with patients and families. The four tiers range from casual contact with patients and families, to staff and volunteers whose primary responsibility is the spiritual and religious care of patients, visitors, and staff. In addition to drawing attention to the importance of roles within organisations and the appropriateness of varying levels of knowledge and skill, the tiers of professional competence also recognise that spiritual care may be "caught" at opportune moments by a variety of staff and volunteers, and not always "delivered" according to set protocols or timeframes.

1.4 Spirituality and aged care

Providing spiritual support in a residential aged care setting is challenging at best (Kristjanson 2006). Depression and dementia are well documented among people in residential aged care, resulting in lower quality of life (MacKinlay 2006). A Ministry of Health report estimated that at least half of the 30,000 people living in aged residential care in New Zealand were affected by dementia (Ministry of Health 2002), while high levels of depression were found in Australian nursing homes (Snowdon & Fleming 2008). Many patients are also affected by debilitating co-morbidities, loss of independence and identity, functional limitations, diminished social contact, cognitive changes, bereavement, and other end of life issues (Kristjanson 2006; Yoon 2006). In New Zealand, financial constraints and an aged care workforce that is both poorly paid and undervalued (Human Rights Commission 2012) compound these challenges.

Against this background of issues, a growing body of research highlights the importance of spirituality when caring for the elderly. A sense of spirituality or religiousness predicts life satisfaction in the elderly (Yoon 2006), increases the perceived quality of life among individuals receiving palliative care (Hermann 2001), and offers protection against despair at the end of life (McClain et al. 2003). The continuity of a person's spiritual life and their sense of self was important to patients with mild to moderate dementia (Lo et al. 2010), while family members perceived the overall quality of care was higher when spiritual care was specifically offered (Daaleman et al., 2008). These findings augment research from Australia, New Zealand, the United States, and the United Kingdom, which suggests there is a "client led recovery of spirituality" (D'Souza 2002; Egan 2010; McCord et al. 2004; Tacey 2003). With the rapidly increasing proportion of elderly people in New Zealand (Bascand 2012), consideration of these issues is a matter of growing urgency.

Despite ever deepening understandings of the connection between health, quality of life, and spirituality, the aged care sector may rely too heavily on mainstream churches to provide spiritual care resources, and there may be a

mistaken assumption that the 'church' volunteer has adequate knowledge and expertise in the provision of spiritual care. Given the divergent spiritual needs of our aging population, there is a need for raising spiritual awareness among aged care staff as a starting point (MacKinla, 2006), followed by specific training of healthcare professionals to support, enhance and extend existing services. Also central to gaining a better understanding of residents' care needs is assessing their spiritual needs at admission, and later as required, to ascertain their hopes, concerns, practices and beliefs in a non-judgmental manner (Kristjanson 2006; MacKinlay 2006).

The literature points to various pathways to spiritual care in aged residential care, including but not limited to, building mutual relationships; providing compassionate settings (Rumbold 2006); offering opportunities for independence and autonomy (Secker et al. 2003) as well as privacy (Ross 1997); looking beyond people's inner life or beliefs (Rumbold 2006); providing a compassionate ear and helping individuals to maintain a sense of dignity (Kristjanson 2006). Hermann (2001) proposes that an interdisciplinary approach is the most appropriate way to implement spiritual care. Furthermore, attending to the palliative care needs of the elderly means assisting patients with their physical, psychological, social, and spiritual needs (Kristjanson 2006), with one not mutually exclusive of the other. Lloyd reminds us it is about showing "the need not only *for* care, but *to* care" (Rumbold 2006). The challenge is that if spiritual care is not well defined and structurally mandated the needs of patients, and their families and whanau, may be inadvertently missed (Egan 2010).

Given the growing literature and interest in spirituality in health care and specifically aged care, it is timely to examine this topic in a New Zealand context. Therefore, we conducted a qualitative pilot study in which we interviewed staff working in a variety of roles about their beliefs about spirituality and spiritual care, and their experiences of offering spiritual care to aged care residents.

2 Methods

Researchers' point of view

Two of the researchers (SW and RE) are trained secondary school teachers, and RE has extensive experience in researching spirituality in a variety of contexts, including education and health. MB worked for several years in a variety of roles in the intellectual disability and mental health sectors, including four years as a part-time caregiver in a group home for intellectually disabled young people.

Recruitment

We purposively sampled four local rest homes, choosing one small rest home; one large facility providing rest home, hospital, and specialist dementia care; one rest home with a religious affiliation; and one large facility operated by a publicly listed company. Telephone contact was made with each facility's manager and information sheets describing the aims of the study and the interview process were provided. At two facilities the manager or charge nurse approached potential interviewees, while at the other two a notice was circulated to staff calling for volunteers. At the facility owned by a publicly listed company, no staff volunteered to be interviewed. All participants were offered a $20 grocery voucher at the end of the interview.

Interviews

A semi-structured topic guide was formulated after reviewing the literature, and we undertook face-to-face interviews with our participants in January and February 2013. The interviews focussed on the participants' beliefs about spirituality and spiritual care, experiences in offering spiritual care, and barriers and potential improvements to delivering spiritual care. Brief field notes were written after each interview to note emerging themes.

Data analysis

The interviews were directly coded from the audio recordings using a generic qualitative approach (Caelli et al. 2003) and framework analysis (Ritchie & Spence, 1994). We made the decision not to fully transcribe the interviews given limited resources, however the importance of the participants' words as they

were being spoken was noted, and salient quotes were transcribed verbatim. Three of the interviews were coded by all the authors, in order to compare our coding schemes and ensure consistency. MB coded the remaining interviews. The topic guide provided the initial themes, and emerging themes and sub-themes were also noted. The framework analysis approach was used to deductively construct a number of overarching themes.

The University of Otago Department of Preventive and Social Medicine Human Ethics Committee approved this study.

3 Results

3.1 Participants

We conducted interviews with 19 staff from three rest homes. Eighteen interviews took place on-site at the facilities, while one interview was held at the University of Otago, Dunedin campus. MB conducted 12 interviews with participants from two facilities. For the third facility, SW conducted six interviews, while MB conducted one interview. Interviews were audio recorded, and all participants gave written consent.

In total, we interviewed five nurse managers, two nurses, eight caregivers, two chaplains, one house manager, and one activities co-ordinator. All participants have been given pseudonyms to guarantee their anonymity. The decision was made not to identify individuals and their comments by their job tiles because of the small number of participants and the narrow range of work roles. We decided the potential harm to individuals who might be identified deductively outweighed the benefits of identifying individuals by their roles.

Most respondents were aged over 40 years old, 14 of the participants were female, and almost all participants self-identified as New Zealand European or Pākehā. Three participants originally came from overseas, and one participant claimed partial Māori ancestry. The number of years of work experience in aged residential care ranged from four to over 30 years. Nine participants stated they

attended religious services at least occasionally. All of the carers had completed at least some of the requirements for a formal qualification in caring for the elderly (typically CareerForce, National Diploma/Certificate, or Certificate in Support of the Older Person). Several of the carers obtained their qualification through their current workplace. While each of the facilities where interviews took place had policies acknowledging the importance of respecting residents' spirituality, specific knowledge of these policies was generally very poor, even among management. Some staff, including staff in senior roles, did not realise their workplace had policies regarding spiritual care. Several participants expressed surprise at the questions we asked, and some revealed they had never thought about the relationship between spirituality/spiritual care and health in relation to their work before being interviewed.

3.2 Ways of understanding spirituality

We asked participants to tell us their thoughts about spirituality and spiritual care. For a very small number of participants who were not sure about either or both of these concepts, we provided broad, non-religious definitions once they had had the opportunity to respond.

Participants expressed a wide range of beliefs about spirituality, which encompassed the breadth of the spirituality continuum (Rumbold 2006). Most commonly, spirituality was understood to be a quality pertaining to the individual, made up of that person's beliefs, values, and personal preferences. "Wholeness" was also commonly mentioned.

> *What makes up a person really. It's about <u>the</u> person – their likes, dislikes, their beliefs, their values – everything about the person is part of their spirituality." (Lois)*

> *It's fairly broad. I see it as being not just of a Christian, Buddhist, or whatever. It's the whole being of that person, it's their whole outlook on life, their whole means of who they are, what they do with their lives, what they've done with their lives. It's the whole lifetime thing with*

> *them within themselves, too. It's not just "I'm reading a Bible" sort of thing. It's the whole being of them, it's in them." (Cheryl)*

Religion was mentioned by about half of the participants, however very few restricted their definition of spirituality to exclusively religious terms (such as church membership or regular service attendance). Most people who mentioned religion saw it as being somewhat separate from spirituality, although not completely distinct from spirituality.

A couple of people thought of spirituality as a relationship or connection to God or a higher power. However, relationships were more commonly framed in reference to family and friends. A couple of participants also suggested more abstract relationships with nature or the universe as being important. Although cultural identity and cultural beliefs were also occasionally mentioned, in general participants focussed on the individual aspects of spirituality. Other concepts included the search for meaning, a sense of inner well-being, and a way of making sense of the world.

A few people also discussed the idea that spirituality and religiosity can develop and change over time.

> *My automatic and in the past response would be religion, but I know it's more than that. I think it's a sense of self and being for that person, things that contribute to their well-being. It may be the music they listen to, family they interact with, just their way of doing things." (Charlotte)*

> *I just think that you realise how important it is to people when they are nearing the end, like some might have never been religious and suddenly they get it right at the end, it becomes important, and others it's never been, never will be… (Debbie)*

3.3 Ways of understanding spiritual care

On the surface, participants' understanding of spiritual care was strongly shaped by their understanding of spirituality. Hence those people who had defined spirituality in purely religious terms were highly likely to describe spiritual care as religious care, those who had conceptualised religion as different from spirituality often mentioned both religious and spiritual care (often juxtaposing one against the other), while those who did not mention religion usually did not discuss religious care. However, on closer analysis virtually all participants described the concepts of respect and fulfilling wishes and needs. For one participant who defined spirituality as church membership and spiritual care as church attendance, it became apparent from their responses as the conversation developed that care involved *respecting* a person's religious choices, whether of the same or different religion of the respondent.

Reflecting the widely held view among our participants that spirituality involves beliefs, values, personal preferences, and acknowledging the "whole" person, most people talked about recognising and respecting these aspects of the person.

> *Looking at the individual as a whole person, seeing that whole person. It's not just about what's wrong with them, it's the whole. (Lois)*

> *To me it means that you're actually looking after the person's – you're looking after that value system, that belief system, and that you are actually providing care that recognises where they are at, and the system that they are operating in. (Judy)*

One participant went further in discussing *how* this was done:

> *Spiritual care is your empathy and how you treat someone, and how you project to someone. You just do what you do, it's how you do….spiritual care to me is a gentleness and a kind[ness], and showing empathy to others. (Sue)*

For many participants, respecting the beliefs and values of residents naturally leads to helping fulfil a resident's wishes and needs.

> *Well, spiritual care, well we're very well aware of different residents coming in, different ethnicities, cultures and things like that, and we try to cater as best possible to their spirituality needs. (Kate)*
> *Spiritual care would probably be a wide variety such as, well for me, it consists of people's needs are being answered, being provided. (Jessica)*

One person was adamant that they did not think spiritual care was, or should be, part of their job ("*We're just the carers; we've got nothing to do with that…")*. But even this person, as the conversation progressed, expressed the concept of respect (i.e. that you need to be careful about the things that are said, that it is inappropriate to swear in front of residents, that residents should not be made to attend chapel if they do not want to). While being very upfront that they would have nothing to do with directly offering spiritual care, this person also expressed that they would follow the wishes of residents, by referring a person in distress to the duty nurse.

3.4 Operationalising spiritual care

After asking participants to describe their understanding of spirituality and spiritual care, we asked a series of questions to find out about the participants' experiences of offering spiritual care. We asked questions about spiritual care at the personal and organisational level. Many of the participants were unsure of specific examples of spiritual care they had offered residents, and initially defaulted to examples of religious care. However, some participants were prompted by the interviewers to consider any type of care as spiritual care, or the spiritual nature of care in general. This caveat should be borne in mind when considering the interpretation of our participants' responses.

Personal level of offering/delivering spiritual care

At the personal level, different levels of relationships between participants and residents were apparent.

Befriending

Most commonly, participants mentioned elements of befriending – sitting, chatting, listening, doing that little bit more. Conversations were often light, not involving spiritual or religious themes, and were initiated equally by residents and staff.

> *They probably touch on things, but it's never an in-depth – it's just a requirement at the time, of someone caring to listen, or someone caring to do what they want to do, or there's not big discussions on a religious basis, but on other needs or other requirements. (Sue)*

A few people specifically commented on the light, joking nature of these exchanges, and a few people mentioned the importance of encouraging memories, although this was considered possibly distressing for residents with dementia.

> *It's usually joking things, like [they say] "You're such a naughty girl, you know where you're going later, don't you?" and they'll point down. I just laugh it off. But other than that no, not unless they have one-on-one… (Cheryl)*

As part of helping to fulfil a resident's wishes or needs, several participants spoke of offering care beyond a person's minimum physical needs. Making the effort to get a resident outside into the garden was frequently mentioned. Other people mentioned organising volunteers to help residents access community resources.

> *Most of the time we just have some pampering with them – some massage on their hands, do their nails, take them out for a walk, and some outings. (Jessica)*

Despite the befriending nature of the relationship many participants cultivated with residents, several people were quite clear that there were certain boundaries at work and that developing true friendships with residents was not

appropriate. Almost all of the participants appeared to feel genuine affection for their residents.

Counselling

Conversations sometimes go beyond joking and befriending to counselling. Many participants seemed aware of their personal limitations in this area, sensing that inappropriate counselling may result in more harm than good. For many carers, the dilemma was easy to solve because the resident could be referred up the chain of command to the duty nurse or manager. A nurse or manager might be drawn into a counselling type conversation with a resident because of this referral, but some participants in these roles also spoke of conversations they had had with residents where topics of a more personal nature had spontaneously emerged. All of the nurses and mangers interviewed said they would be comfortable with referring a resident on to the chaplain or an outside advisor if it was an issue they were unable to handle.

> *…if you just sit with them and talk, it will be surprising what comes out. I mean, often you spend half an hour with someone and as you think you're finishing the time you've spent with them, they may come out with something and you think "Oh my goodness", so that does happen. (Katherine)*

> *…often it can be people don't know what is bothering them, but once you start talking and once you start digging a little deeper, it's often, you know, something will come up that they hadn't actually realised themselves. (Lois)*

When asked how residents respond when given the opportunity to talk in this way, one participant commented on their feelings of relief.

> *Often with relief because they get to talk about it. And they know what is said to us is confidential, and that we respect their belief systems, and even though we may not be able to – sometimes it's difficult to*

> *understand what they need so you've got to explore a little bit more until you find what you need – and they are very understanding, they are willing to explain and clarify things. It's relief most of the time. (Helen)*

An important sub-theme to emerge was *time* – not only do conversations take time, but the relationships that enable these conversations to take place also take time to develop.

> *Taking time to listen to the person, that's all they want sometimes is someone to take the time to listen to them… (Charlotte)*

> *It's hard when they first arrive because you don't know them. I think it is something that you develop over time….I think over time, I think more often over time, it's from the time that you know, they get to know you and they get to trust you, and they will start to open up, share. (Judy)*

However, in the hectic world of aged residential care where one staff member may be responsible for over half a dozen residents during a shift, or where one chaplain might be expected to minister to several hundred residents, time is a luxury, with one respondent commenting about the difficulties of *"triaging time" (Stephen).*

End-of-life care

The responses of several participants indicated that a particular type of relationship develops with residents as the person nears the end of their life. This type of care incorporates both befriending and counselling, however the finite amount of remaining time for the resident seems to free some people to ask the larger questions, and draw more people into the relationship. It was clear that some participants saw it as a profoundly moving experience and honour to care for residents as they were dying. As one participant said:

> *The only times I talk about it is in their last days or hours when they know they are going to pass away. And then we quite often talk about it, but other than that it doesn't really get brought up. (Glenda)*

This same participant also spoke in detail of the care she offers to the dying:

> *Especially some of them who know they are dying, they say, "I like this" or "I wonder if I could do this", and you just talk to them, and soothe them, and rub their head, you know. It's an honour, it really is. (Glenda)*

Another participant spoke of the nature of these conversations, and the challenges she perceived, for herself and the residents:

> *Sometimes, if they're getting near – if they're getting towards the end of the trail if you know what I mean – then I kind of talk to them about it. Talk a little bit about death. It is uncomfortable though, really. Unless they are very settled in themselves, you know. I don't know – you need to find the right time, and the right resident to talk, and sometimes they talk to you about it. They say, "I'm ready to go, I'm not afraid you know. I've lived a really good life – if something happens now I'll be happy". You – and you just kind of sit down and they – usually what ends up happening is they talk about their life a bit, things that they've accomplished, their family, and how they're tired and just ready to go…. (Kate)*

Many participants also spoke of comforting residents.

> *A lot of the spiritual care that you are giving is really that end of life comfort…(Judy)*

> *…we still try and distract them and comfort them, even just holding their hands or wiping their forehead, or you know. It's just that personal touch; that contact with another human being. (Cheryl)*

For some participants caring for someone *after* they had died, such as helping prepare the body for burial or cremation, or attending the person's funeral, was not only a way to process their own grief and say good-bye to a resident, but was also a form of spiritual care, of honouring their memory.

Another participant spoke about providing spiritual care for the resident's family.

> *At the time it's very hard, but you're not only delivering to the resident, but to the family and friends who are coming in as well, so it's that observing the privacy, giving them empathy, giving them cups of tea sometimes, or bringing them in here and giving them a hug and listening, so on that level you are practicing all these things. (Sue)*

This participant also made an interesting observation about the spiritual care residents offer each other, and the dying resident's family.

> *We had someone who was dying here not so long ago, and the family really appreciated not only what the staff were doing, but what the residents were doing for the lovely little lady….Even now the family are still coming back to see some of the residents who sat with her, and got her drinks. And so it becomes a channel of care, and it's a privilege to do some of these things. (Sue)*

These last quotes illustrate that spiritual care not only comes from the relationship between staff and residents, but also between staff and families, and residents and families.

Facilitating family involvement

Many participants mentioned the importance of involving families in a resident's care, not only at the end of life. Families were actively encouraged to visit their family member, to attend events at the facility, and participate in the routine of their family member, such as riding in the van on outings.

> *...family are really important for a person's spirituality. And so just the fact that we have no visiting hours, families can come and we try and invite then in at any time that suits them, whether it's before they go to work or late in the evening to say good night. (Lois)*

Participants said they had, or would, approach a family member about a resident if there were any concerns, particularly if the resident consented. Carers were less likely to approach family directly, but would make any concerns known to the nurse or manager.

A few people also mentioned how family can be a source of stress for the resident, particularly if they have not been involved with the resident or there has been family trouble. One participant mentioned the need to tread carefully, lest the family perceive the staff member was meddling into family business.

Religious care

Two of the facilities have on-site chapels and regular chaplains, while the diversional therapist at the third facility organises a regular on-site worship service. When we asked participants to describe the spiritual care they or their organisation offered to residents, many people would often default to religious care examples (i.e. encouraging the resident to attend chapel or see the minister), especially when discussing what they might do in certain hypothetical situations to help a resident.

A few participants mentioned having conversations about religion with residents, but these were usually on the level of asking about church membership or attendance, or asking if the resident would like to see a religious advisor.

> *Usually I ask what religion are they, are they a religious person or not, what kind of religion do they believe, do they go to church. (Charlie)*

Only a few participants said they had ever directly referred a resident to the chaplain. Referrals to the chaplains were more likely to be made by nurses or managers, particularly at the stage when the resident was experiencing problems.

> *Sometimes we can't always do something, sometimes as for my job is to facilitate somebody else to come in and do that fulfilment. (Helen)*
> *Sometimes [~~~] will ask me to go see people with particular pastoral challenges. What that usually means is that these are particularly difficult people. It's kind of end-of-the-line stuff and I'm supposed to pull off a miracle. (Stephen)*

Many of the carers said if a resident was in distress they would follow the chain of command and pass the matter on to a manager or nurse.

> *And they approach me as a carer for my advice, I would say, "Don't you worry about this right now, we'll sort this out", and that's when I'd approach the RN or a senior person. (Cheryl)*

Although some carers said that they would consider directly approaching the chaplain about a resident, unfamiliarity with the chaplains seemed to act as a barrier for some, and both chaplains commented on the need to allow relationships with staff to develop over time.

Only one participant who was not a chaplain said they sometimes prayed with residents. However many participants openly acknowledged their limitations (and sometimes feelings of discomfort) when it came to Christianity or other faiths.

> *But we don't openly use – because we're not trained – so we don't openly use things like sitting and praying with somebody, unless they requested it. Because I wouldn't feel comfortable because I'm not trained in that spiritual aspect. So I feel that is an area where you could perhaps do more damage. (Judy)*

> *As far as spiritual questions go, I understand myself to be limited to certain criteria. But certainly somebody from a different – Hindu or Muslim, or any other religion – I certainly couldn't fulfil that. (Helen)*

One participant talked about the experience of having a Buddhist resident, and alluded to the twin themes of respect and fulfilling wishes and needs.

> *It was a bit overwhelming at first, because it was the first probably Buddhist or Indian person that we'd had here, and we were a bit nervous about it. But I mean, she was fine with it, and she would just tell us what she needed, what she wanted, and her family was very good too. (Kate)*

Spiritual care at the organisational level

Policy

One facility had a specific written policy pertaining to the spiritual health of the older person. This document included definitions of spirituality, the impact of spirituality and spiritual distress on health, guidelines for personally supporting residents' spiritual well-being, and organisational procedures. Another facility had a spiritual and cultural policy, while the third had an overarching policy about offering support to people.

Generally, participants had poor knowledge of their facility's policy contents, even among management, and some people (management and carers) were unsure if such a policy existed. Despite the lack of detailed knowledge, most people felt having a policy made a positive difference to the workplace, by helping to raise awareness of the importance of spiritual care.

Spiritual needs assessment

At all three organisations, the formal in-take assessment for new residents included a few questions about the person's religious, spiritual, and cultural beliefs and desires. A nurse usually conducted these assessments, and families often participated, although neither chaplain had ever been involved in the initial

assessment. No participant mentioned specific "tools" such as a structured spirituality assessment (e.g. the Daily Spiritual Experience Scale, or the Functional Assessment of Chronic Illness Therapy Spiritual Well-being scale). Residents were typically asked about religious membership, if they wanted to attend services, if they wished to speak to a religious or spiritual advisor, funeral arrangements, and other spiritual or cultural needs (e.g. dietary requirements). The space allotted to writing about a new resident's religious, spiritual, and cultural needs on in-take forms ranged from half a page to a full page. As one participant admitted:

> *Religion, cultural, and spiritual needs are usually lumped together. (David)*

Aside from the initial needs assessment, which is used to write the resident's formal care plan, there was little evidence of pro-active, on-going spiritual needs assessment. One facility has regular resident satisfaction surveys, but the questions tend to ask about religion rather than spirituality. Staff at all the facilities are expected to contribute to the residents' care notes, although several people mentioned the variable quality of the documentation, and conceded this was a general area needing improvement. Spirituality needs were only documented if someone noticed a change in a resident, such as if they expressed a desire not to attend church service anymore, or if there was a specific problem. This information would be used to update the resident's care plan.

> *I don't go back like three monthly and look at the spirituality page to see if there is anything. I do review it six monthly, the whole care plan, so I can review it then, but unless there are problems, or unless they have problems with us or something….then we just adjust and write it down in the care plan then, and I'll tell the care givers, and make a note of it and stuff. (Kate)*

At one facility a few people mentioned that very sensitive information would deliberately not be documented for privacy reasons, and instead brought to the attention of the nurse or nurse manager. Carers at all of the facilities mentioned

that they felt comfortable approaching a nurse or manager if they noticed a change in a resident.

In-service training

A wide variety of in-service training opportunities on a range of topics are offered at all of the facilities, and many of the care staff had completed formal qualifications in aged care through their workplace. One facility offers a yearly in-service training on spirituality, while another facility was planning on running sessions on spirituality soon. At the third facility, the induction training incorporates spirituality into the larger concept of valuing the lives of people. Not all the staff we interviewed had done the in-service training offered, but of those who had, most of them found it useful, especially in raising their awareness of different belief systems.

3.5 Barriers and Improvements

Participants discussed a large number of barriers to offering spiritual care to residents, and suggested some possible improvements. These have been grouped into categories relating to staff, residents, the staff-resident relationship, and the organisation/aged care industry.

Staff

Lack of personal awareness

Several participants commented that a lack of personal awareness of spirituality might be a significant barrier.

> *I think it's your own spirituality, because really it's your own values and beliefs systems that can be a barrier right at the beginning….I think it's an awareness of your own self really, and if you don't have a good awareness of your own self, and your own emotional and mental stability, I think that, you know, that can be a barrier. (Judy)*

> *I think sometimes it does come down to just changing the way you think, just making people, making our staff more aware that spirituality*

> *is more than religion, that it is about the whole person, what's important to them. (Lois)*

One person made an interesting comment that spiritual/personal awareness may not always be conscious:

> *I don't know how often some people think about it really. Like I say, people that do care will probably be doing it without realising that they are, and others that don't probably wouldn't think about it…. (Charlotte)*

The point was also made that training focussed specifically on spirituality may put people off, if they do not acknowledge their own spirituality or that of others.

> *I think the training needs to be incorporated as part of overall training, because for some people if you said we are going to hold a workshop on spirituality, a lot of people would say "No, don't want to go to that". Whereas if you had a training session on care of the elderly and as part of that you had a session on spirituality, then that would encompass a lot more people. (Judy)*

Fear of imposing unwanted care

The fear of overstepping boundaries and imposing unwanted and potentially harmful spiritual care was a significant concern raised by many people, with one person commenting *"you would hope that you would leave them no worse than you found them." (Nigel)* One participant spoke of a particular case she had heard of where the "spiritual care" offered by a staff member at a particular facility had contributed to a considerable amount of distress and anguish for a woman and her family while she was dying.

> *So I think in a way you can overstep your role. I mean, just that you have to be really sensitive to whether they are asking for your input, and that you're not just preaching at them. (Kate)*

> *I think it is important not to put your own – not to be pushing your own religion on to people. Because we're here, it's just not our role. We're here to look after them from a health care perspective, and to assist them of their own spiritual beliefs and ideas, rather than put our own things on to them. And I guess that's quite often what can happen. (David)*

> *We're very careful that we don't try and push anything on to a resident, so you've got to be careful about suggestions that you make… (Judy)*

> *When everybody thinks so differently, it's a touchy subject really. And they're very vulnerable, elderly are very vulnerable, and I think that we have to be really careful. (Glenda)*

In addition to the personal relationship boundaries highlighted above, another participant spoke of role-related boundaries.

> *There are barriers in that one has to be careful not to overstep your role. But also, and I guess that will vary from person position, I mean RN, carer. The carer might absolutely have it spot on, but they have to be very careful, you know, that they don't go outside the parameters, and all of us are in that, but we obviously have different parameters…occasionally families get a bit nervous about, you know, if anyone in their view is going outside the parameters, because it might be that they see they are poking into family business or whatever. (Katherine)*

While there might be prescribed boundaries dictated by a particular role, in the personal relationship with residents boundaries were also seen as flexible and something that needs to be discovered.

> *I think it's probably fluid, and I think that you probably know when a resident needs to have some spiritual input. (Kate)*

But I think you do have to discover your boundaries. Just like normal boundaries in care for people. (David)

Related to concerns about appropriate boundaries, a lack of confidence was also discussed by some participants, particularly those who are occasionally called upon to engage in a counselling-type relationship with residents.

To a degree I feel comfortable, but I haven't trained as a minister or a chaplain or anything like that, so I would be reluctant to go beyond what I thought was my – my scope and knowledge really. (Judy)

Probably, if I felt a bit more comfortable with death actually, you know what I mean. It's a scary thing. I mean – and unless you are really comfortable with it, and there is nothing to panic about, you know….I'm not there yet, but I wish in a way I felt more comfortable about the whole thing…. (Kate)

While almost everyone commented that there is good support within the organisation, there was also a sense that some people were struggling on their own to provide this level of support for residents, particularly if there was no specific person to whom a resident could be referred on to. In contrast, several of the participants whose roles did not require them to engage in counselling, or who had a clearly defined referral pathway for residents, expressed confidence in their ability to help residents.

Probably averagely confident, because we can't always help them, but we can always pass them on to the minister who can help them. (Debbie)

I always feel comfortable because I take everyone as I find them. (Sally)

Residents

Spirituality = Religion

Some people commented that residents' own perceptions of spirituality were a barrier to offering care.

> *…getting behind what people see as being spirituality, because a lot of them haven't really thought about spirituality. And as I said, it's often just religion, and to try and get beyond the "just religion", you know. "I don't want to talk about it anymore, I've told you I'm not interested in God". And it's like, "Yeah, but what is it that does interest you?" "Oh, football." "Oh, well let's talk about football", you know. So they don't actually see it as being spiritual, as being part of their spirituality, but we do. (Lois)*

At the same time, a few people commented on generational and societal changes influencing our perceptions of spirituality.

> *… a lot of that generation wouldn't see spirituality as anything other than religion. So, and that's changing isn't it now? And probably up north a lot more, like different cultures. We lack a bit of that down here in Dunedin, so yeah, we're good old Scottish and English stock – church is the only sort of spirituality, or expression of spirituality. (David)*

A diversity of beliefs was sometimes seen as positive, with one participant commenting on how having a resident who practiced a non-Christian religion had helped residents see things in a new way. In contrast, other participants mentioned how residents who follow an evangelical faith may sometimes interfere with the rights of other residents by preaching to them. In general, participants thought it would be a good thing to increase the awareness of residents that spirituality is more than religion, and one person suggested having more resources such as posters or booklets talking about spirituality, and listing resources or advisors to turn to for help, would be beneficial.

Unresolved issues

Although few of the participants said they had ever noticed a resident in spiritual distress, some people commented on the difficulty of helping residents with unresolved issues.

> *Particularly when they're at that point where end of life is close, some of that distress is, while it's not said – I'm quite sure a lot of – some of that distress is not pain, it's actually unresolved issues, I think. Spiritual issues, because I've seen people that, yeah, they just haven't resolved their issues and yes, some of them are quite distressed. (Judy)*

> *People who have not achieved spiritual peace in some way, they do – are very distressed, and they do try to hang on to life. (Helen)*

While several people commented that most residents die peacefully, it appears from the quotes above that the spiritual needs of some residents are not being adequately met while they are alive, particularly at the end of life.

Health challenges

Especially in relation to residents with dementia, health challenges were seen as a significant barrier to providing spiritual care.

> *From our perspective probably the biggest barrier is their dementia. It is about actually getting behind the dementia… (Lois)*

Some people mentioned the dullness of everyday life in a rest home, and more meaningful activities were suggested as a way to help enliven people.

> *I think more activities that will keep them occupied during the day will be good, because it will direct them to the idea that "I have to enjoy life", not just a matter of getting bored in here and just sitting. Some old people just say, "Oh, same old every day, sit here and get bored." So I think more activities will be good, more productive activities that they really want. (Jessica)*

Relationship issues between staff and residents

Developing a personal relationship with the resident

Participants spoke about the need to develop a relationship and establish trust with residents before broaching spiritual topics.

> *…it is a very private thing, and they are just not too sure how things would go. Who to trust really. (Helen)*

> *If you haven't built up a relationship it is very difficult. And I would expect more of the anti-, the anti- sort of reaction, if you haven't got a relationship, because they could feel like you are interfering… (Judy)*

Differences in personality were also seen as inhibiting relationships.

> *We have to be realistic that some people will connect with some people more than others. (Katherine)*

Another participant who was involved in conducting in-take assessments also commented on feeling awkward having personal conversations with someone they had just met.

> *I find it very difficult myself welcoming somebody into a facility and saying, "Well, ok, you know when you leave, do you want to be…" you know. (Kate)*

A few participants suggested much more could be done to help prepare staff to engage with residents at the deeply personal level, including tools for structured spiritual care, and on-going formal supervision.

> *I think that, you know, we could do a lot more in actually teaching how to – how to make that connection, that is safe. (Judy)*

> *It would be nice to feel a bit more comfortable, to be able to go into things a bit more in depth rather than just skirting over it….If we had a*

page on spirituality that you could actually talk with them about their beliefs, it they chose to. (Kate)

Organisational/structural issues

Staffing and time

Several participants mentioned a lack of staff and time as barriers to being able to deliver one-to-one care.

From my point of view it would be great to have more staff, and to have more staff to be able to actually do really in-depth stuff with spirituality with the residents. Particularly the one-on-one things, to be able to have that time. (Lois)

More time, more carers. I think that's what it comes down to in some respects, time and people, and maybe having the right people to be involved with that. (Charlotte)

However, unless the funding structure for aged residential care changes, these challenges are likely to remain in the long-term.

Task orientation

Participants also spoke about the task-oriented nature of the job being an impediment to offering spiritual care. Particularly for carers, there is a limited amount of time to complete a long list of tasks each shift, and it is understandable that they are focussed on the immediate duties at hand.

You're working with them all the time and you don't think about these things. (John)

We were on the task but not the person, so I think that the more we can see that the health and well-being of somebody is a total thing, and that it's the spiritual as well as the physical, and the mental, that needs to be dealt with…but how you get that through I don't know. (Lois)

Other people commented on the nature of their organisation.

> *It's a kind of a Martha-type organisation rather than a Mary kind of organisation – it's a doing. (Nigel)*

> *…the reality is it is a hospital, you have people with so many different needs. (Katherine)*

Considering the non-stop demands many staff face, it is not surprising that organisations have had to develop a task-oriented culture; otherwise, essential physical care needs may not be met. However, this culture may be at odds with being able to offer truly holistic, person-centred spiritual care to all residents. One participant suggested regular refresher training would be useful.

> *Sometimes I think just to have that update, you know, just to bring your mind back to "Actually, I've forgotten. I've got so into the task oriented, I've forgotten about the important stuff. (Lois)*

Low morale

A few participants also commented on the lack of value that New Zealand society places on carers of the elderly, and low staff morale.

> *If you've got carers going in there who are stressed, trying to make things meet in their own home, and they're going to work…there is a lot of disheartedness out there….The thing is they need backing, and if they don't have that backing, how the heck are they supposed to do a good job when they are feeling low themselves? (Cheryl)*

> *That's why staff morale matters, too. It's always interesting going into a home and watch whether staff are interacting directly with the punters or just ignoring them. (Stephen)*

4 Discussion

Key findings

Our participants expressed a variety of beliefs about spirituality that covered the spirituality continuum, from individualism to a relationship with a higher power (Rumbold 2006). However, most participants, including those actively attending religious services, thought of spirituality in terms of an individual's beliefs, values, and personal preferences. This way of thinking about spirituality also seemed to be reflected in our participants' lack of differentiation between spiritual care and holistic care, although most participants did perceive a difference between spiritual care and religious care. Some respondents discussed their own spirituality in detail, however not all of our respondents were as forthcoming, and this likely reflects feelings of uncertainty on the part of respondents, and the fact that most of our respondents were meeting the interviewers for the first time.

In general, a participant's understanding of spirituality shaped both their view of spiritual care, and the type of spiritual care they offered residents. People who thought of spirituality as encompassing beliefs, values and personal preferences, gave examples of care that were centred on respecting those aspects of the resident. For participants who perceived spirituality as a relationship with God or a higher power, the search for meaning, or connection with the universe or nature, spiritual care also involved engaging in a counselling-type relationship with receptive residents.

We noticed a general pattern of what appeared to be role-related differences (i.e. managers and nurses compared to carers) in the depth of responses and insights offered by participants. (All the managers we interviewed had also trained as nurses.) These differences may reflect different opportunities for education, training and on-going professional development between nursing and caregiving staff, however it is important to note that several carers also offered considerable insight into their own spirituality and their practise of spiritual care, and that not all managers were equally perceptive. The nursing profession has been at the forefront of incorporating spirituality into models of care for

several decades, and nurses and managers are in the position to be able to attend workshops and conferences, and to develop personal interests such as palliative care. Many of the carers mentioned that spirituality had been a component of their aged care qualification, and most of them had done their facility's in-service training sessions, however the focus of most training was naturally on the practical parts of the job (e.g. lifting, physical needs), and less on the "being" aspects of care. Several people stated in-service training about spirituality and spiritual care had been beneficial or would be welcomed, particularly in regards to increasing personal awareness.

While virtually everyone interviewed said there was good personal support offered to staff within their workplace, low wages, lack of acknowledgement for the difficult job they do, and little support from within the aged care industry or government to improve working conditions are obviously taking a toll on the workforce. Lack of staff and time were also cited by several people as barriers. However, it was clear that virtually all of the participants seemed to express genuine affection for their residents, and that many of them found the relationships they developed with residents to be personally enriching.

Despite the development of sometimes close relationships with residents, it was also clear that many of our respondents were fearful of imposing spiritual care onto residents, and that offering unsolicited spiritual care was perceived by some participants as potentially crossing professional or role-related boundaries. Several participants also pointed out that the framing of spirituality and spiritual care had to be carefully managed, for both residents and staff. Some participants felt residents viewed spirituality with suspicion, and that talking explicitly about spirituality or spiritual care might be off-putting for some residents and staff.

While the basic organisational infrastructure (policies, general needs assessment at in-take, on-going in-service training) for spiritual care appears to be in place, this does not appear to be translated into explicit spiritual care practice, and respondents in general seemed uncertain about their ability to offer spiritual

care. Thus, as noted by Egan (2010), there is the possibility that the spiritual needs of residents are going unrecognised and unmet. However, some people also commented on the stoical nature of today's elderly, and a few expressed the view that for many elderly, religion is the only expression of spirituality. Barriers to spiritual care may therefore be coming from the residents themselves, in addition to staff and the organisation.

Comparison with models of spiritual care

Winslow and Wehtje-Winslow (2007) proposed five ethical principles of spiritual care, including understanding each patient's spirituality, following the patient's wishes, not imposing spiritual care, understanding one's own spirituality, and proceeding with integrity. Our respondents repeatedly mentioned the importance of following residents' wishes and not imposing spiritual care, while the examples of care they described were consistent with the personal values they expressed when discussing spirituality. Our respondents' level of insight into residents' spirituality was less clear. Many respondents said they had never noticed a resident in spiritual distress and some seemed surprised by the question. Nevertheless, caregiving staff in particular seemed well attuned to changes in residents' behaviour or mood, and were willing to offer comfort immediately, or seek assistance from higher up the chain of command if necessary.

From a measureable, managerial perspective, the Consensus Conference (Pulchalski et al. 2009) outlined several operational principles, including spiritual assessment, spiritual care models and treatment plans, inter-professional team training, continuous quality improvement, and personal and professional development. Many of these principles appeared moderately well-embedded in the facilities where we conducted interviews. The in-take assessment at all three facilities included questions about identity, religion, spirituality, and cultural beliefs. However, there was no evidence formal spiritual assessment tools (e.g. FICA Spiritual History Tool, FACIT Spiritual Well-being) were being used, and one respondent responsible for conducting in-take assessments felt more guidance and structure in this area would be useful. There

was also no evidence that spiritual care models or treatment plans were formally integrated into a resident's care plan, aside from support for that person to attend worship services or see a chaplain or clergy member, if requested. However, as noted before, possible resistance from residents to consider spirituality in a wider sense means these issues need to be handled with sensitivity.

Gordon and Mitchell (2004) discussed tiers of professional competence, ranging from staff whose primary responsibility is providing spiritual and religious care to residents, staff, volunteers, and family, to staff who have only casual contact with residents and families. However, no facility where we conducted interviews employed any full-time, on-site spiritual care staff, although chaplains and religious lay people seemed to be frequent visitors. The participants in constant, regular contact with residents (i.e. caregivers) were doing an admirable job of meeting the residents' daily needs and providing grassroots spiritual care through comfort and companionship. The caregiving staff by and large appeared to have a very respectful and tolerant attitude towards different beliefs, recognised when their personal limits had been reached, and were unafraid to ask for help or refer a resident on to management.

Strengths and weaknesses

The qualitative nature of this project allowed us to explore issues in greater depth than if we had simply surveyed people, and our participants' range of work roles contributed to the richness of the responses. Almost all of the respondents were open to discussing our questions, and many were willing to reflect deeply on their personal beliefs and experiences.

However, our participants were a purposefully selected group of people, and our findings are not readily generalisable to other facilities or the aged care sector in general. Another limitation is related to the inexperience of the two interviewers. After reviewing the full audio recordings, it was clear that a few participants were asked very leading questions. In these cases it was sometimes extremely difficult to disentangle the responses of the participants from the spoken

thoughts and running interpretation of the interviewer. In light of these limitations, our findings must be viewed with caution.

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