THE IMAGINATION OF CARE:

Caregivers' perspectives on end of life care in rest homes

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Abstract

This study explores and examines the roles of caregivers within rest home facilities in New Zealand; and specifically, how they unpack and deal with managing the tensions associated with end of life (EOL) care. It adopted a qualitative perspective to enable an exploration of how the experiences of caregivers help guide their practice and understanding of their roles in relation to EOL care. A grounded theory framework was utilised in order to explore how caregivers make meaning and find value in the roles they perform within rest home facilities.

This study offers insights into some of the tensions that caregivers face in a working environment where life and death occur simultaneously. It was apparent that caregivers are aware of the many social taboos they must negotiate in order to conduct their work. It was also apparent that they understood that others might perceive their work as dirty but that this did not prevent them from finding job satisfaction and create meaning in their work. Instead, they created meaning by using the conceptual tool *the imagination of care*. This involved utilising their imagination and past experiences to enable EOL care which represented the dying rites of individual residents but also fitted within their ethic of care.

Chapter One: Introduction

Introduction

While I thought I was learning how to live, I have been learning how to die

Leonardo da Vinci

I have never felt afraid of being around a dead body. This is perhaps largely due to my fairly traditional Māori upbringing. *Tangi* which is the Māori term used to describe death and bereavement helps to celebrate the life of an individual who has just died with song and laughter. The practice of *Tangi* was something I came to understand from at an early age as offering comfort during the time immediately following death. Even as children, we were encouraged to touch and sit by the bodies of our dead relatives and participate in *Tangi* practices. We would hear stories of the deceased's adventures and misadventures, and through this process I have always felt that even the most dysfunctional of families can, for a few days, feel a total sense of togetherness and collective understanding. I was raised in a family environment where *Tangi* practices and *Marae* protocols where taught from a young age. I think in hindsight this has helped with my death and dying curiosity as I recognise now that having these early experiences of death and bereavement ensured that I can participate in, and be more comfortably part of these processes. This I believe has consequently led me to feeling less unsure or lifted many of the social taboos associated with EOL care and death and dying. While part–Japanese, I was raised through a traditional Māori upbringing. I speak of being part Japanese later in this chapter, however, as a child I was adopted and asserting my Japanese identity is something that has only occurred as an adult.

These early experiences taught me to respect death but in no way fear it; I valued the philosophy that whilst this individual may no longer have a physical human presence as we once knew, they are not totally gone. They linger amongst us, within the relationships we once shared, through our memories of them and the memories triggered by their prized possessions, and memories associated by their usual haunts (excuse the pun).

It was not until my first year at university when I began to re-explore some of these values that I had somehow forgotten as I grew up and moved away from my family environment. In my first year at university, as part of the sociology 100 level programmes, I had the pleasure of being re-introduced to my curiosity with death and dying by Ruth McManus; this brief encounter made me realise that not everyone viewed death and dying in the same way, and indeed I realised that many of my friends had not had the experiences of dealing with death and dying at all. This realisation as an adult made me feel lucky to have had the experiences with death practices that I had had as a child.

Later in my first year at university, my dad became very unwell and part-way through exam week I received a phone call to come home because "it wouldn't be long now". This phone call was devastating; my dad had always been my quietest but biggest supporter. I arrived home to find a shell of the man who I had once believed was indestructible.

I had the honour of being able to help nurse my father in his final journey and we managed to keep him at home, which meant a lot to both of my parents. This was my first experience with death workers.

What did surprise me at the time, and made me fairly upset for some time afterwards, was that my dad's general practitioner (GP) had not explained that he was stopping his medications because he was dying. I felt that the GP ought to have explained what was

happening to my dad, that this would have been the decent thing to do, and that he owed him that. Instead, however, for a few days my dad and our family were left confused about what exactly was going on.

Our hospice doctor finally explained to my dad that he was dying; I had only seen my father cry once before in my life. He was not crying because he was dying, (he may not have processed this yet) but because he was worried that he did not have all of his affairs in order.

These experiences taught me some significant life lessons that would become all that more important a few years later. These were that clear and concise communication must occur when an individual begins the dying process, this includes the dying individual as well as their family, and that considering and articulating how you would like to die is a subject that should not be avoided.

Dad passed away within a week of me being told that he was dying and my arrival home. The morning he died I walked in to his bedroom to say good morning and I knew that he would die soon. I had learnt about the "death rattle", which refers to breathing patterns, from Ruth in the 100 level sociology paper. I recall now, with some surprise, that I instantly thought about this course. It was hard to see dad like this and he died shortly after.

We dressed dad's body at the funeral home. This practice is of significant cultural value to my family as it is considered important that a body be surrounded by family as much as possible. We followed the hearse home and were all welcomed back on to the family home by a traditional welcome, which included a *karanga* (formal welcome), *waiata* (song), *karakia* (prayer) and *hongi* (the sharing of breathe and life). Anybody who arrived to pay their respects to my dad was welcomed in this manner. His *tangi* reflected who he was and made coming to terms with our loss a lot easier. In my eyes, *tangi* allow responsibilities to be

shared and thus grief is shared. I still miss my father and while I do have regrets about not being able to articulate just what he meant to me before he left this world, I have found some peace in the belief that he is still with me.

A few years later, I was in need of a part-time job, and a friend's mother, who was a manager at a local rest home, offered me a caregiving job. I took it to provide a means to an end, but it helped me take another important step toward embarking on this thesis journey.

At first I was overwhelmed by the job; it was not until my first death that I think I found my place within this rest home. Whilst I began to really enjoy my work and I discovered a new found respect for the individuals that I worked with and cared for, I was astonished by some of the death practices; these practices just seemed so foreign to me. I began to quietly ask other caregivers questions about how dying was handled. I became the "but why?" caregiver, but the patience that these caregivers demonstrated with the residents they also afforded to me, and they patiently attempted to respond to my constant questions. They would answer me honestly and often discuss the regrets that they had felt as caregivers.

Death in my experience is often not discussed within rest home environments; I can to a degree understand how this lack of conversation occurs but at the same time I believe that with discussion comes an opportunity for discovery. One of my most profound experiences whilst working as a caregiver came while looking through one resident's album of photos that she had taken while she worked in Japan as a registered nurse (RN) after World War Two. At this time we also found an old journal extract and I sat on her bed and read it to her. I said to her afterwards, "Did you ever imagine that one day you would have a half Japanese girl read this back to you?" She said, "no" and we laughed. After this we had a very long discussion about her regrets in life, her thoughts about where she was now, and the manner in which she now wished she would die.

People's reactions to the fact that I was working in a rest home were interesting. The first point that would be raised was that I had to "wipe bums", then that I had to shower, dress and feed people. "How can you do that?" was often the next question. I found it very interesting that this narrow focus was based on physical cares. My friends and family had no idea what really went on in a rest home and they were often shocked by the fact that I was working with the dying and the dead. This made me begin to seriously question where people believe older individuals die and the expectations society holds about how and where death should occur.

I believe that rest homes create a culture of death silence, and that therefore room must be made for discussion and recognition, not only for the residents but also for the caregivers. This must be done to ensure that our collective ignorance of death can be displaced and replaced by a culture that acknowledges that everything that lives will eventually die, and that learning more about dying can teach us how to live better.

The impetus for undertaking this research therefore has many layers. I wanted firstly to acknowledge the context in which caregivers currently work, and to develop a deeper understanding of how they cope both physically and emotionally with caring for rest home residents during and after the dying process. I also wanted to explore how other caregivers had learnt to cope with their profession. I met with Ruth and we began to discuss my ideas about research. This is when we approached Kate to become my other supervisor to which she agreed.

As I began to explore my research topic, it became apparent that caregivers operate in an environment where many contradictions occur; both in regard to care philosophies and practices. To help understand the contractions and conditions which have fostered the culture and environments in which rest homes operate and which have informed this thesis, it is important to start by outlining the social context in which dying in New Zealand occurs.

The social context of dying in New Zealand

Death and dying and more specifically EOL care is a component of life which is influenced by many factors. As a means to introduce the study, it is important to outline the social context of dying in Aotearoa today. This involves detailing the demographic trends and social status of caregivers. It is necessary to consider the broader demographic context in which Aotearoa as the emerging trends impact directly on the social organisation of EOL care today. Likewise, understanding the status hierarchy that informs care work helps to make sense of the many socio-economic and political factors which interact to create the space in which EOL care is constructed.

Demographic trends and EOL care

Contemporary New Zealand society is undergoing significant demographic changes. Research has established that Aotearoa is an ageing society (Badkar, Callister & Didham, 2009). What is more, global rates of dementia are predicted to increase by up to 50 per cent by 2020 (O'Rourke & Tuokko, 2000, p.390). Moreover, life expectancies are increasing and fewer individuals are having children (Badkar, 2009). Such demographic shifts have significant implications for aged care patterns (Badkar, 2009), including that caring patterns are likely to shift from the community to private facilities such as rest homes or hospitals (Ahmad & O'Mahony, 2005) and children no longer being considered the main provider of care for their parents in their old age (De Vaus, 1996). Discourse surrounding older age welfare provision for EOL care within Aotearoa is currently mixed, specifically in regard to where responsibility falls for the financial provision for retirement and the cost of care associated with this phase of life. On the one hand the New Zealand government has been

encouraging and directing citizens to save for their retirement privately through private and workplace pension schemes. On the other hand, the belief in "cradle to the grave" welfare is still prevalent within Aotearoa and it is the expectation of many New Zealanders that the government will provide care for them in times of need throughout their lifetime but especially during old age. These mismatched expectations have led to a potential gap in provision. While there is a mix of private, workplace and government pension schemes, there is a low uptake of private pension schemes by New Zealanders. In 2011, only 1,679,442 out of 4,483,205 of New Zealanders were enrolled with the Kiwi Saver Scheme (KiwiSaver, 2013).

Whilst the Old Age Pension has not significantly changed over time, governmental funding of EOL care has. The eligibility criteria for entering a rest home have become more stringent over recent years (New Zealand Labour Party, New Zealand Greens and Grey Power (Labour/Green/Grey), 2010). One effect of the increase in rest home entry criteria for individuals who lack private funding is that they remain in their private homes for longer periods of time (Badkar, 2009). When these individuals finally meet governmental funding criteria, they enter into rest home environments with more advanced dementia and more chronic degenerative medial diseases, and they are more likely to be in need of EOL care (Badkar, 2009; Human Rights Commission (HRC), 2012).

Where older New Zealanders die

New Zealand like many other OECD countries has made attempts to reduce the number of older individuals living in institutional settings. In 1994, the Health and Social Policy ministers of OECD countries reached an agreement about the overall objective for policies for the care of frail older people: 'Elderly people, including those in need of care and support should, wherever possible, be enabled to continue living in their own homes, and where this

is not possible, they should be enabled to live in a sheltered and supportive environment which is as close to their community as possible, in both the social and geographical sense' (Labour/Green/Grey, 2010, p.20-21). Despite this initiative in seeking an overall policy objective, rest home occupation has continued to grow (Labour/Green/Grey, 2010, p.18). This increase in occupation has also meant that more older individuals die in rest home or similar facilities, and not die at home like many express to happen (McNamara & Rosenwax, 2006) For instance Broad, Boyd and Connolly (2011) found over 40 per cent of the over 65 age group die in rest home or similar facility. As noted by Seymour et al. (2005), McNamara and Rosenwax (2007) and by Gott and Ingleton (2011) older people still view dying in one's home as the most preferable place to die but they are now less likely to die where they want than in the past.

Whilst 45 per cent of aged residential facilities are registered to provide palliative care in the form of the Liverpool Care Pathway (LCP) which indicates a desire of these facilities to provide good EOL care, there is no data or research on how much of an impact this pathway is currently making within these facilities (Palliative Care Council of New Zealand (PCCNZ), 2013, p.11).

Current trends in the care industry in Aotearoa

In 2010, more than 42 000 individuals received care in nearly 700 certified facilities (Labour/Green/Grey, 2010, p.18). This number has grown from 28 000 individuals over 65 living in residential care in 2005 (Smith, Kerse & Parsons, 2005, p.1448). Of these 42 000 individuals receiving care, 57 per cent were rest home residents, 31 per cent were in private hospitals and 8 percent received care in dementia units (Grant Thornton, 2010, p.76). Furthermore, 64 per cent received a government subsidy to pay for their care with 32 per cent not meeting subsidy criteria (Grant Thornton, 2010, p.76).

Historically, aged care in Aotearoa has mostly been provided by faith based or not-for-profit organisations and this is still largely the case in other Westernised countries such as Australia. However, this has dramatically changed within the New Zealand context over recent decades as over 65 per cent of residential facilities operate as for-profit organisations (Grant Thornton, 2010, p.32), with 33 per cent of rest home beds available nationally being provided by six large organisations (Labour/Green/Grey, 2010, p.18). The privatisation of residential care facilities in New Zealand is potentially creating gaps in the provision of care available, in terms of who can financially afford care and choices available being largely based on financial circumstances (Grant Thornton, 2010). This inequality is also apparent when considering older individuals in rural communities; nationally only 13 per cent of rest homes are located rurally (Labour/Green/Grey, 2010, p.18).

Government spending on individuals over the age of 65 in Aotearoa has also steadily decreased and is well below OECD recommendations (Labour/Green/Grey, 2010, p.21). In 2005, New Zealand only spent 4.2 per cent of overall governmental spending on individuals over 65 years of age, although OECD recommended levels at this time for New Zealand was 7 per cent (Labour/Green/Grey, 2010, p.21).

The combined effect of reduced government funding, expensive private services, and many New Zealanders not having enough money to pay for their aged care needs is that higher proportions of older New Zealanders are remaining within their private homes for longer and whilst this is a valued aspect of ageing it has implications for when these individuals do enter rest home facilities (Badkar, 2009). When they enter care they do so with more complex healthcare needs than in the past (Bebbington et al., 2000). It also can impact effective EOL communication (HRC, 2012) being achieved in terms of formal paperwork, along with building meaningful relationships with caregivers.

Demographic trends in caregiving and caregivers

Current research has identified that by 2036 more than 48 000 caregivers will be required to meet the current projected number of older individuals requiring care in New Zealand (Badkar, 2009, p.3; Badkar, Callister & Didham, 2009, p.1). This is of note given that future projections of caregiver numbers will fail to meet this demand (Badkar, 2009).

Caregiving, specifically by rest home caregivers, is an under researched area and the many broad generalisations made, such as caregivers having low status, being low skilled or underpaid do little to demonstrate how this profession functions.

More than 33 000 individuals work in the aged care sector, including, caregivers and nurses, most working on a part-time basis (Grant Thornton, 2010, p.10; Labour/Green/Grey, 2010, p.18). While it employs a not insignificant proportion of the country's workers, the work is not evenly distributed. The caregiving industry is highly gendered, with over 90 per cent of caregivers in Aotearoa being female (Badkar, 2009, p.3). The report by the HRC (2012) highlighted some of the factors which maintain the high gender disproportion within this industry. These factors included wages being considered too low for a male to provide for his family, low status of the occupation, gender role expectations, and resident preferences for female carers (HRC, 2012). This professional group is also an ageing population, with many caregivers set to reach the governmental retirement age of 65 years within the next 20 years (Badkar, 2009, p.3).

Staffing levels and workloads within rest homes

In terms of staffing levels and workloads within care homes, under the Aged Related Residential Care Service Provider Agreement (HRC, 2012; Wardle 2012), facilities are able to develop their own staffing ratios. However, while it is unclear how they work out what

staffing ratios are appropriate, it would seem plausible that financial reasons would contribute to decisions about resident to caregiver ratios. Prior to the introduction of certification in 2002, Registered Nurse (RN) staffing requirements for high dependency or hospital level facilities was one full time RN to every five hospital residents; therefore a 45 bed unit would require nine RNs (HRC, 2012, p.63). This requirement seems unlikely to have been met as many researchers have noted that older care is unable to attract nursing staff, because there is considerably less professional support and considerably more stress than in other settings (Wardle, 2012).

Current Ministry of Health guidelines recommend that for adequate rest home level care 1.7 hours of caregiver time and 0.3 hours of RN time should be spent per day per resident. Dementia patients should have two hours of caregiver time and 0.5 hours of RN time, and hospital level patients should have 2.4 hours of caregiver time and one hour of RN time (HRC, 2012, p.16; Grant Thornton, 2010, p.110). However, these are voluntary guidelines, and in many instances these recommendations are not met (Badkar, Callister & Didham, 2009; HRC, 2012; Kiata & Kerse, 2004). Existing reports suggest that many facilities leave a sole caregiver on duty at times, although it was noted that this was probably less likely to occur at high demand times, such as during the morning shift (Labour/Green/Grey, 2010; HRC, 2012).

Many rest home staff have identified that weekends and night shifts can be a particularly vulnerable time as there are significantly fewer staff members during these shifts (Labour/Green/Grey, 2010). It was also found that when financial savings need to be made within facilities, perhaps due to low levels of occupancy, staffing levels were the first cutbacks and these positions were often hard to fill once occupancy was back up (HRC, 2012).

The issue of staffing levels may also influence the rates at which aged care residents are admitted to acute hospital services. In 2008, it was found that admissions to acute services were 27 per cent higher in New Zealand when compared to international admission rates for the elderly (Labour/Green/Grey, 2010, p.46). It has been suggested that this highlights that many potential hospital visits could have been prevented if older persons' illnesses had been diagnosed and treated at an earlier stage before complications developed (Labour/Green/Grey, 2010).

Providing a living wage

Caregiving work is not valued highly in New Zealand in terms of providing a living wage. Caregivers are one of the lowest paid professions nationally (Badkar, 2009; HRC, 2012). At the same time rates of pay for equal or similar work vary considerably across this sector, which suggests that the fragmented and non-unionised nature of this industry influences the rates of pay. Penal rates do exist in some private facilities where there is a collective agreement; however, caregivers rarely receive the same penal rates or increased rates for working weekends or night shift when compared to their district health board (DHB) counterparts (Labour/Green/Grey, 2010). Many facilities suggest that they cannot compete with remuneration rates offered by DHBs and have to rely on other strategies such as overseas recruitment and training packages to attract and retain staff. This itself is an interesting claim when the funding which pays for wages largely comes from DHBs. It would appear that how funding is allocated once it is paid to different organisations operating care facilities differs considerably across those organisations (HRC, 2012).

In 2009, the average hourly wage for caregivers was $14.40, ranging from $19-$12.55 (HRC, 2012, p.45). The amount of pay received after tax and with travel costs deducted for rural community care workers ranged to as low as $7.20 for 75 minutes of work (HRC, 2012,

p.40). This issue, of not being provided with a living wage, is further compounded by other costs and inequities in caring work that include, for instance, inconsistent working hours, having to pay for one's own immunisation or screening for super bugs such as methicillin-resistant Staphylococcus aureus (MRSA), and lack of pay parity between private and publicly funded rest home caregivers and their DHB counterparts (HRC, 2012). It has furthermore been noted that within many rest homes, maintenance staff, such as gardeners and unqualified chefs, are on higher hourly rates than caregivers within the same facility (HRC, 2012).

Staff training and registration

The capacity to give good elder care relies on certain standards, for instance of hygiene and infection control, being met. Many occupations require training and have levels of certification and professional codes of practice, however, there is currently no registration or enrolment of caregivers in New Zealand. This means that they work without a professional code of ethics and without professional codes of practice which can be enforced by courts of law (Smith, Kerse & Parsons, 2005). Consequently caregivers are reliant on their employer to provide supervision and training as well as the facilities to create and foster environments which are safe and ethical for staff as well as residents.

Training requirements

Currently, there are no minimum training requirements for being a caregiver, except in regard to dementia care (Labour/Green/Grey, 2010; HRC, 2012). This point is highlighted by the HRC report, (2012, p.73) which found that 46 per cent of residential caregivers have no formal training. Levels of training are even lower in community care services, where 61 per cent of community based support workers having no formal qualifications.

It is clear that this is a highly un-regulated workforce (Fallon, 2006). Whilst there are nationally recognised training programmes specifically for caregiving, there is little incentive to undertake such training (Labour/Green/Grey, 2010; HRC, 2012). Caregivers are often expected to undertake training in their own time. The financial cost of training and up-skilling is also not reflected in their level of pay (Badkar, 2009; HRC, 2012). Currently there is no dedicated governmental funding to provide educational training for caregivers (Smith, Kerse & Parsons, 2005). Most caregivers instead learn on the job and develop their skill sets through the observation and advice of other caregivers (Smith, Kerse & Parsons, 2005) and other medical professionals such as RNs. However, it has been found that access to professional support and supervision only occurs rarely and opportunities for such learning are minimal (HRC, 2012; Smith, Kerse & Parson, 2005). Consequently, according to Kiata and Kerse (2004) residential care facilities are often perceived negatively and employment structures lack clear career pathways (Badkar, Callister & Didham 2009; Blaser, 1998; Fallon, 2006).

Staffing retention

Staff turnover is high within this profession (Badkar, 2009; Badkar, Callister & Didham, 2009; Fallon, 2006; HRC, 2012; Morgan, 2005) and it is clear that many of the above mentioned factors of low wages, high workloads and a lack of educational upskilling support contribute to this issue. Labour/Green/Grey (2010, p.36) found that staff turnover is especially high within the first year of work, with up to 56 per cent of caregivers leaving this industry within their first year of caregiving. This first year turnover was also found for RN who work in elder care, with up to 46 per cent leaving in their first year (Labour/Green/Grey, 2010, p.36). Despite this high turnover within the first year of employment, staff turnover actually deceases with years of experience (HRC, 2012). Staff turnover translates into

discontinuity of care, which is likely to impact on the quality of care provided (Morgan, 2005). With high staff turnover, knowledge pertaining to residents is lost and this has consequences for overall care because, for example, caregivers are often relied on by physicians and families to provide information about the health status of rest home residents. High staff turnover also impacts on staff morale. It is clear that the caregiving industry lacks clear career pathways and that this impacts on staff retention and recruitment (HRC, 2012; Blaser, 1998).

Workload

In terms of workload, the scope that caregivers must now work within has increased significantly. As the HRC report, (2012) found, caregivers are now dealing with heavier client loads, including, increased complex medical, increased social, emotional and psychological problems which take considerably longer to deal with. Increased managerialism, leading to increased paperwork requirements, means that caregivers spend less time socially interacting with residents (HRC, 2012). The issue of heavier workloads needs considerable addressing especially when exploring the incidence of disability and dependency trends of individuals' over the age of 65 (HRC, 2012). Badkar (2009, p.14-15) found that in 2006, 32 per cent of individuals aged 65-74, 51 per cent of 75-84 and 71 per cent of people aged over 85 had reported some form of disability. This is of noteworthy as the prevalence of disability is likely to continue to increase, meaning that older individuals will need considerably more help with assisted daily living (HRC, 2012).

The issue of excessive workload is demonstrated by the new roles that caregivers now undertake. Caregivers are now more likely to undertake tasks which were historically undertaken by RNs, such as wound management and the distribution of medication, including controlled drugs (Labour/Green/Grey, 2010). This practice of delegating more complex tasks

to caregivers is further promoted by the fact that caregivers are a cheaper option than RNs (HRC, 2012). Wardle (2012) added that recruiting more nurses into aged care is unrealistic, as RNs prefer to work in other settings where there is more clinical support available and less responsibility. Given these factors, it seems unlikely that this issue of clinical responsibility moving into the caregiver domain will change in the foreseeable future. In many facilities caregiver responsibility in many facilities now includes secondary type roles, such as laundry and cleaning which are generally included within current caring timeframes (Morgan, 2005). The issue of increasing and broader workloads in elder care contributes to high staff turnover, high stress levels and errors.

This point was evident in the HRC (2012) report where it was found that many caregivers had been told by management not to speak with residents to reduce time spent with them.

Legislation

Caregivers lack significant professional power; there are several reasons as to why this seems to occur. There is currently no professional body for caregivers to ensure that working conditions are safe for this group, and to ensure that they carry their duties out ethically. What is more, caregivers are not subject to regulatory requirements, such as the Health Practitioners Competence Assurance Act 2003, which mandates registration, vetting and qualification requirements for most professionals within the health industry (HRC, 2012).

It would appear that rest homes are not guided by as much public policy or legislation as most other working fields, specifically work in other areas of care. Previous legislation such as the Old People's Homes Regulation 1987 and Hospital Regulation 1993 are no longer included in current legislation for rest homes (Labour/Green/Grey, 2010). Currently there is no legislation pertaining to staff ratios and this means that staffing ratios are decided upon by

the facilities themselves (Labour/Green/Grey, 2010; Wardle, 2012). This can be compared to the situation in child care facilities, which organisations are required by law to have standard staff to child ratios. This legislation was put in place in the belief that children are a significantly vulnerable group within society. At least some older persons who are being cared for in rest homes are arguably similarly vulnerable.

Auditing process

Audits are one way in which the quality of rest homes is currently checked, but it would appear that opinions regarding this practice are rather mixed. Audits are undertaken to provide accreditation for rest homes; the maximum accreditation period is for three years. Further audits may be carried out at any stage during this three year period if problems or issues are identified (Labour/Green/Grey, 2010). Many issues have been identified with the auditing process; including that rest homes can choose an auditor to conduct the audit and know well in advance when an audit will take place (Labour/Green/Grey, 2010). This prior knowledge means that rest home managers can bring in extra staff and resources when an audit is expected (Labour/Green/Grey, 2010). The auditing process is undertaken by two auditors over a period of two days with more than 200 audit criteria for certification to be checked. Consequently the auditing process focuses mainly on compliance, managerial process and mitigating risk instead of measuring and enhancing quality of care (Labour/Green/Grey, 2010). Failure to meet some standard during the audit process does not mean that a rest home will not be certified; instead this will usually result in a shorter certified time period (Wilson, 2009). Since 2009, spot or unannounced audits have been undertaken but these only occur after a complaint has been made (Wilson, 2009). Many believe that spot auditing is a better way to assess how effectively care is being delivered, but opinions about who should be conducting these spot audits vary (HRC, 2012;

Labour/Green/Grey, 2010). Wilson (2009, p.27) suggested that without transparency of spot audits 'commercial sensitivities' are placed above consumer rights. What is more, if rest homes are failing to meet standards of care and there is no public accountability, then there is no incentive to improve.

The next section focuses on the social status of caregivers as the symbolic value placed on care is just as important as the formal social organisation of the profession.

The social status of caregivers

Hierarchy of care

When we consider the social status of caregivers, it remains evident that caregivers are at the bottom of the hierarchy of care. This was demonstrated several times in the HRC (2012) report which stated that managers do not consider that caregivers have an important part to play in the development of residents' long term care plans, even though they spend a considerable amount of time with these individuals. It is, however, currently unclear whether residents also do not believe that caregivers are part of their care plan team.

Lack of support mechanisms and support networks

Caregivers face a substantial amount of tension within their roles. As noted earlier, workloads are increasing and so too are the number of expectations that caregivers must fulfil. It has been found that many caregivers feel unsafe in raising concerns with their management specifically in regard to staffing levels (HRC, 2012). What is more, many caregivers are now required to sign confidentiality agreements. This is perhaps understandable given the nature of their work, but these agreements extend to when a caregiver no longer works at these facilities (HRC, 2012).

Whilst the lack of support mechanisms and networks is apparent for many caregivers, it is particularly evident for migrant caregivers (Badkar, Callister & Didham, 2009). Migrant caregivers may depend on a specific employer for their work visa. This may explain why many migrant caregivers feel that they are unable to express concerns about workplace conditions and feel obliged to work any shifts without negotiation, meaning that at times migrant caregivers are working 15-16 hour days (HRC, 2012; Badkar, Callister & Didham, 2009). The lack of support mechanisms and networks is particularly relevant for migrant workers because bringing more migrant workers to work in the care industry is a suggested strategy for meeting the future demand for paid caregivers (Badkar, 2009; Badkar, Callister & Didham, 2009; HRC, 2012).

Whilst the issues of training and workload have already been discussed, these issues also impact negatively on the support mechanisms and networks available to caregivers. As noted, caregivers may rely significantly on learning on the job but as Smith, Kerse and Parsons (2005) found, interactions with residents for RNs or Enrolled Nurses (ENs) were rare. This lack of interaction between residents, caregivers and RNs or ENs may mean that informal and formal opportunities for care workers to feel supported and raise concerns are limited.

Currently, there is little literature or evidence to show that support mechanisms and networks exist to help caregivers deal with the emotional and physical tolls that this line of work takes (Mezey, Miller & Linton-Nelson, 1999). There is little evidence of any recognition being given that having such support systems may improve the care of both residents and caregivers.

Respect and dignity for caregivers

Dignity and respect have a fundamental value to any worker; however, many argue that care is a marginalised and devalued role within Western societies (Gray & Heinsch, 2009; Mezey, Miller & Linton-Nelson, 1999; Shemmings, 1996). Its low status is evidenced in the previously discussed factors of low pay, lack of education and training, and a feminised workforce. This devaluation sits in an interesting relationship with HRC (2012) finding of a growing shift away from the ideological belief that children are responsible for the care of their ageing parents in Western societies. When this shift in ideological belief patterns about responsibility for care combines with the demographic trend of most Western societies having ageing populations, the outcome is a growing ageing population demanding individualised care plans combined with the responsibility for care shifting from the private to the public sphere. These shifts in the ideology and social organisation of care place the care industry in an interesting situation. While one possible and logical outcome might be increased demand for and so increasing dignity and respect for a more professionalised workforce, this has not come to pass because of the prevailing devaluation of care, especially care undertaken by women. The shift from informal to formal care, when combined with the low status given to those care seems to have the effect of contributing to the low levels of respect and dignity that caregivers receive.

Despite this ongoing depreciation of their employment status, many people and especially women continue to work in the care industry for significant periods of time, as discussed previously under staff retention. Exploring this contradiction, some commentators point out that feeling respected and being acknowledged can be a way to modulate dissatisfaction with issues such as low pay, low social status, emotional and physical tolls often associated with providing care (Morgan, 2005; Shemmings, 1996; Stacey, 2005). This raises the question of

how do care workers achieve a sense of respect and acknowledgment in their work, as it is not apparent in the formal employment structures.

In summary, the social context of dying and caring for the dying in Aotearoa is shaped by specific demographic trends and a complex status hierarchy, both of which profoundly influence caregivers' experiences of providing EOL care. The focus of this thesis is to examine how caregivers negotiate these kinds of contradictions whilst undertaking their job.

Organisation of the thesis

This chapter introduced the focus of the thesis by outlining the personal motivation for and a contextual account of EOL care in Aotearoa. It sets out the current context of care work to highlight key tensions caregivers must negotiate. It also identified some of the social perceptions which exist around this industry and how these perceptions influence the manner in which living and dying is done within rest home facilities. Subsequent chapters focus on the aims, research methods, findings and analysis that make up the body of the thesis.

Chapter two examines current debates in the EOL care and caregiving literature to clarify gaps in formal understandings of caregivers' experiences. The review highlights the need to know more about how caregivers' experiences shape their ethics of care. Identifying this gap in the literature clarifies the aim of the study which is to examine and create understanding about how caregivers deal emotionally and physically with EOL care for rest home residents.

Chapter three outlines the methodological approach used to investigate the thesis question. It outlines in detail how participants were selected and how the data was gathered and analysed. This chapter also outlines ethical and research considerations as well as discussing some methodological reflections.

Chapter four is the findings chapter where themes that emerged in the data analysis of interviews with participants are identified. Chapter five further unpacks these themes to reflect on and engage with existing debates associated with the sociological analysis of EOL care. This chapter also introduces the concept of the *imagination of care* as a means to explain how caregivers' manage the various tensions associated with their duties. The conclusion, chapter six, provides an overview of the thesis argument and, while noting its limitations, outlines its potential contribution to existing understandings of how caregivers' combine their experiences and ethics of care.

Conclusion

Care workers operate in an environment where many contradictions occur in regard to EOL philosophies and practices alike. This chapter has given an overview of many of the tensions in which care currently exists, such as staffing levels, providing a living wage, staffing retention and legislation. The next chapter outlines key debates in the EOL care literature.

Chapter Two: Literature Review

Introduction

Understanding the dynamics of caregivers' work is complex as they are responsible for multiple aspects of care, but, as was shown in the preceding chapter, it could be said that they do not receive many of the benefits or privileges that are associated with their considerable responsibilities. In this chapter literature that highlights the complex nature of caregiving work has been examined so as to identify important themes and gaps in existing knowledge and understanding of EOL care work. Some of these topics were broadly canvassed prior to interviews taking place. They were re-investigated in more depth after being out in the field where their importance was established in discussions with caregivers about how they deal with EOL care, and how they frame the work which they undertake.

The chapter first outlines historical and contemporary approaches to the social organisation of dying before outlining key theories, issues associated with communication practices, attachment within rest home facilities, the use of emotional labour and how grief work is conducted, creating meaning, and, briefly gender and language.

Historical approaches to death and dying

Historically in Western societies, dying occurred within the privacy of one's home (Meier, Morrison & Sean, 1999), however, this approach has significantly changed due to new technological, professional and institutional processes (Field & Cassel, 1997; Howarth, 2007) that are now attached to this stage of life. These processes occur against a background of societal beliefs presuming that old age is considered the right time to die, because death in old age signifies the completion of life (Howarth, 2007). Other beliefs include that 'older

people's deaths are 'natural', relatively straightforward and 'on-schedule'. Consequently they are not considered to be in need of 'special care and support' (Howarth 1998, cited in Lloyd, 2004, p.237). Attitudes such as the aforementioned have shaped and influenced the way in which EOL care has been provided to older individuals in Aotearoa and has led to many assumptions that older people somehow know how to die.

Contemporary shifts in death and dying

There have been considerable shifts within contemporary death and dying practices and ideologies. Whilst many individuals still identify their home as their preferred death location, most people in Western society now die in some institutional setting (Porock, Pollock & Jurgens, 2009). The notion of the right time to die has also begun to be challenged; increased longevity and life expectancies mean that expectations that death is appropriate from the age of 65-75 no longer seem relevant (Howarth, 2007). Indeed, perceptions such as that old age signifies poverty, a loss of control, disability and failing health are becoming better recognised as having led to stigmatisation of the aged (Howarth, 2007). In terms of Aotearoa, it was identified by the HRC (2012) report that the baby boomer generation may be challenging many of the current practices and assumptions not only on how we age but also on how we die.

Theories relating to death and dying

There are many theories which examine the death and dying experience, and these have helped to contextualise the experiences of the individuals involved within this process. Little research appears to currently focus on industries such as rest homes, specifically from a caregivers' perspective. This is of interest as Walter (2012) suggested that grief and feelings

about death and dying relate directly to social expectations and this is important as social expectations about how rest homes operate are currently mixed.

Death and dying are often framed as either a good death or a bad death, but the manner in which death occurs depends on many factors, such as presence and type of illness, cultural or religious beliefs, age, gender and socio-political context. This discussion will try to establish some of the universal perceptions that underpin a death as either good or bad within contemporary Western society.

A good death

A good death is considered a death that is without pain, comes after a long and successful life, and presupposes that the dying person will be at peace with their circumstances and location and have some control over final events (Froggatt 2007; Lloyd 2004; Lloyd, White & Sutton 2011; Sidell, Katz & Komaromy, 2000). Field and Cassel expanded on these ideas by highlighting the relevance of the environment and those within that environment 'one that is free from avoidable distress and suffering for patients, families and caregivers; in general accordance with patients' and their families wishes; reasonably consistent with clinical, cultural and ethical standards' (1997, p.82). Lloyd (2004) continued by noting that a good death should satisfy broader cultural norms, social expectations and the needs of those that are close to the dying person as well as the needs of the person who is dying. In terms of those who undertake EOL care, McNamara, Waddell and Colvin (1994, p.1504) highlighted a statement made by a nurse who was a participant in their research about what constituted a good death, where they stated that 'it's a good death when you feel comfortable with the scenario. When you feel you've participated'. Statements like this demonstrate that all individuals involved with the dying process have perspectives on what it means to achieve a good death. Those perspectives impact on what might happen in practice.

Adopting a palliative approach

Understanding what a good death is may be enhanced by adopting a palliative approach. According to palliative care literature, a good death also includes choice and control over treatment, spiritual and emotional support, control over aspects of timing (Lloyd, 2004), including the ability not to have life prolonged, open awareness of one's dying condition and that one's affairs are settled (McNamara, 2004). Also, that communication is transparent and that some form of death acceptance is achieved (Zimmermann, 2012).

Differences in a palliative care and rest home approaches to EOL care

Whilst there appear to be some universal commonalities in what constructs a death as good, differences do exist between palliative care and rest home approaches to EOL care. These differences occur because the underlying philosophies of rest homes and palliative care currently do not match, and practice is impacted by that mismatch (Katz, 2005). Palliative care tends to focus on particular terminal illnesses, meaning that older individuals are less likely to be referred to this service compared to younger individuals (Lloyd, 2004). The lack of referrals for older individuals occurs for several reasons, but one significant reason is that death trajectories, which are the perceived courses of dying (Strauss, 2000) are more ambiguous in the elderly (Dwyer at al., 2010), and this makes it more difficult for these individuals to fit into palliative care pathways (Katz, 2005). The dying process for the elderly today tends to be more extended than historically noted (Field & Cassel, 1997), and the complexity of chronic and co-morbid conditions among rest home residents makes it difficult to recognise and therefore manage the terminal phase (Seymour, Kumar & Froggatt, 2010).

Theories relating to a good death vary and that variety leads to differences in how EOL care

is approached, particularly between hospice and rest home settings.

Communication

Communication regarding EOL care

Communication practices in regard to EOL; specifically within rest home facilities are often

disorganised and piecemeal. Several researchers (Field & Cassel, 1997; Mathie et al., 2011;

Shemmings, 1996; Siddell, Katz & Komaromy, 2000) noted that communications pertaining

to residents death wishes are often left till it is too late. This practice is likely to be

compounded by the fact that many rest homes now operate as commercial enterprises and the

notion that dying occurs within these spaces is not an ideal advertisement for their care

services. These researchers noted that death discussions often do not occur formally as rest

home managers want residents to settle in to a facility, or discussions are conducted in a

rather ad hoc fashion (Lloyd, 2004; Siddell, Katz & Komaromy, 2000). The lack of attention

to or unintentional avoidance of death discussion means that a significant function of rest

homes may not be performed. For most individuals who enter a rest home facility this will

more than likely be where they die and it is likely that there would be no further opportunities

for such discussions to take place in the day to day routines of a rest home.

The parallel provision of care in rest homes

The multiple kinds of care that rest homes provide tend to run in parallel. While it will be the

same carers who work across the different types of everyday and EOL care, the tasks and

duties are kept relatively separate. One way to describe this is to see the organisation of care

as bi-directional and the organisation of care routines are perhaps one way to illustrate this bi-

directional nature. When a resident is deemed well, a caregiver may assist a resident with

care routines which encourage continued social participation and engagement within the rest home and wider community, such as, communal eating, exercise or hobby groups or outdoor excursions. However, when a resident begins the EOL phase, caring tasks become more orientated towards comfort and social inclusiveness becomes less of a priority.

By suggesting that rest homes operate in a bi-directional manner, I am not suggesting that they are organised in a competing or conflicting manner, EOL care just happens differently and apart and there may not be a lot of crossover: they exist in parallel and work in two directions, toward on-going life and toward EOL.

Rest home responsibilities pertaining to communication

Responsibilities pertaining to gathering EOL communication are currently rather unclear but there are some suggestions as to why this lack of communication occurs. Shemmings (1996), HRC (2012) and Labour/Green/ Grey (2010) all highlighted that there is a lack of consensus and a lack of clarity regarding professional responsibilities in initiating EOL care discussions. This is compounded by the fact that there are few legal requirements regarding collection of formal EOL wishes and there are few EOL processes in place within most rest homes. If EOL conversations are conducted, this is done in an 'as and when' ad hoc manner (Mathie et al., 2011, p.3). Rest home facilities are legally required to address do not resuscitate (DNR) orders but these do little to attend to people's wishes about the manner in which they would like to be cared for when they begin the dying process. Thune-Boyle et al. (2010) found that due to the lack of clarity regarding communication obligations, families are seldom advised of the terminal nature of illness such as dementia and because of this; discussions pertaining to EOL care are not conducted at an appropriate time. This lack of clarity as to when and how EOL communication should be conducted is likely to be linked to the highly ambiguous state in which care work is undertaken within rest home facilities.

Comparison of communication between rest homes and palliative care within hospices

There are considerable differences in regard to communication practices between rest home facilities and palliative care within hospice settings. Palliative care is fundamentally based on open communication with the integration of living and dying as one goal, and whilst it has been identified that living and dying occur concurrently within rest home facilities, rest homes fall short in regard to this aim of openness. Death practices tend to be undertaken covertly within rest home facilities due to not wanting to upset other residents (Shemmings, 1996). Froggatt (2007) identified that a major difference between rest home death practices and palliative care is that rest homes tend to focus on easily measured aspects of care, for instance, note taking and visible policy. Conversely, harder to manage aspects of care such as attention to EOL wishes, and attunement to deterioration and changing needs of the individual, or emotional and spiritual care, all of which are significant goals of palliative care, receive little attention within rest home facilities (Hegarty & Currow, 2007).

Barriers to effective communication

Despite there being apparent differences in how EOL communication is undertaken between rest homes and palliative care within hospice settings, barriers to undertake effective communication do exist. Apart from there being few legal obligations in regard to EOL communication, barriers exist in achieving effective EOL communication in rest homes. Although in most cases rest home residents are not seen as passive participants of their care, the ability for the residents to take responsibility for the way in which they die (McNamara 2004), which is a fundamental goal of palliative care, may be harder to achieve or seem less likely to occur within rest home settings. This is because more residents are now entering rest home care with higher levels of dependence than previously observed (HRC, 2012;

Labour/Green/Grey, 2010), meaning that resident information, if gathered, may be obtained via secondary sources such as family members or medical professionals.

Communication in relation to EOL care is problematic, with many institutional barriers that get in the way of EOL conversations between residents and caregivers. The limits of communication are significant because good communication is central to interpersonal relations and are an important aspect of attachment.

Attachment

Since within this thesis participants used the term attachment to describe their relationships with rest home residents, this term is used within the discussion in chapter five. Attachment is essentially the bond between individuals to ensure healthy emotional development (Drewery & Claiborne, 2014). Whilst initially much research around attachment theory, specifically Bowlby's research, was in regard to the bond between the infant and mother for the survival of the infant (Drewery & Claiborne, 2014), attachment is a concept that is relevant throughout our lifespan as we attach to other significant individuals, such as partners and friends. Within this research, the focus is on attachment between caregivers and residents.

The term attachment was also employed in the literature search to explore if and how other researchers had linked the concept of attachment with caregivers and with theories on EOL care and death and dying. It has been found that having meaningful relationships are a significant aspect of dying (Howarth, 2007; Shemmings, 1996) and that such relationships can help ease fears or anxieties that the dying individual or their family may have during the dying process (Lloyd, White & Sutton, 2011).

Resident attachment to caregivers

Whilst attachment forming may be considered a process which occurs early on in life, Shemmings (1996) highlighted this aspect of care within her research, noting that residents often enter in to rest home care in a highly vulnerable state. Furthermore, many losses usually precipitate entering rest home facilities, such as loss of the family home, community, friends and community participation (Shemmings, 1996). Given the number of losses that individuals entering rest homes may have experienced, it could be considered an understandable reaction for residents to look to caregivers for a sense of security and comfort.

Caregiver attachment to residents

Several researchers have noted that caregivers forming attachment with rest home residents' is prevalent within the industry (Mezey, Miller & Linton-Nelson, 1999; Morgan, 2005; Shemmings, 1996; Wilson & Daley, 1998). Shemmings (1996) found that caregivers are susceptible to forming attachments with residents, especially when residents have few family members or friends within close proximity.

Attachment forming at the EOL is complex, because relationships often do not involve some typical interchanges that occur in normal socially recognised attachment relationships, such as overt reciprocation. Lack of overt reciprocation, for example through difficulties in speaking after a stroke, means that residents may not be able to acknowledge or thank a caregiver who is providing care (Shemmings, 1996). Despite this, Shemmings (1996) found that caregivers could tell that a resident was grateful for the care they provided.

Potential issues associated with caregiver attachment

Whilst it has been noted that attachment between caregivers and rest home residents do exist, research has found that tensions can exist due to these attachments (Mezey, Miller & Linton-Nelson, 1999; Sidell, Katz & Komaromy, 2000). For example, Mezey, Miller and Linton-Nelson (1999) found that in some cases caregivers felt protective of residents, and resentful of some families who they felt were interfering with care. Also, caregivers are often warned not to become too attached to residents but at the same time, as Shemmings (1996, p.93) found, that caregivers who maintained an emotional distance from residents or did not demonstrate attachments were perceived as 'cold' or 'unfeeling' by their colleagues.

Attachment work can make an impact on the caregiver's sense of self and while this can lead to satisfaction in relationships, it is also a personally and professionally demanding aspect of care work. Unlike many other industries, it appears that there is minimal training and a lack of insight into the impact of care work on the professional and personal self of caregivers, meaning that there are minimal support mechanisms or support networks to help caregivers be emotionally safe while conducting their jobs. It is unclear why attachment and its impact on workers receive little attention both in terms of practice and literature. It is possible that attachment work is hidden by workers themselves, perhaps because they do not want to appear unprofessional in how they conduct their work. The impact of attachment work may also be minimised as a result of the many gendered stereotypes which surround caring, for example, that women are more emotional than males and displays of emotion may be perceived as trivial or inappropriate.

The grief work and emotional safety of caregivers

Emotional labour

In many respects caregivers must perform and demonstrate a considerable amount of emotional intelligence (Bailey, Murphy & Porock, 2011) and emotional labour to conduct their work. Emotional labour according to Hochschild (2003) is the public management of emotions, either by inducing or supressing feelings to outwardly portray competence to others. Li (2005) stated that emotional labour is a significant tool for professionals within commercial or health care settings. Mann (2005) and Larson and Yao (2005) added that emotional labour involves the regulation of emotional displays in an attempt to meet organisational based expectations specific to a role. It is clear that caregivers perform emotional labour, given the situations they witness and work within. However, due to a lack of research into the impacts of work on caregivers, including a lack of research into the impact of the ambiguous contexts within which rest homes operate, such as caring for the living and the dying simultaneously. It is currently unclear to what degree this labour is recognised by caregivers, or how they experience this aspect of their role.

Comparisons to palliative or hospice settings

When rest homes are compared to palliative or hospice settings, differences in terms of emotional work are apparent. Cain (2012) found in her research of hospice workers that they were encouraged to show emotion in their work. For example, many hospice workers had cried openly whilst at work. Cain (2012, p.399) further found through her own experience as a hospice volunteer that they were taught 'a new set of feeling rules around the expression of sadness' and that 'by the end of training I noticed that many of the students were less uncomfortable with their own crying and more able to show their feelings in line with this

new set of feeling roles without apologising'. What this highlights is that whereas hospice environments allow staff room to grieve, it is unclear whether or not this occurs in rest homes settings. But by not having this room to grieve it seems that opportunities to discuss death and create meaning of this process are marginalised.

Despite this importance, relationship related functions which caregivers undertake are taken for granted and recognition of this aspect of their work is minimal. The HRC report (2012) suggested that there is minimal recognition of relationship building by rest home managers that includes lack of recognition within residents' long term care plans, caregivers not being recognised as having expertise within the care industry, and caregivers not having a recognised function with care schedules (Kaasalainen et al., 2010).

Burnout

Providing emotional care over an extended period of time, especially when this is undertaken without adequate recognition and support can lead caregivers to experience compassion fatigue (van Heugten, 2011). Unrelenting fatigue may eventually lead to a more serious condition called burnout. Burnout can occur as accumulated fatigue continues over a period of time and can lead to a loss of ability to connect empathically and increased cynicism towards such things as clients or organisational values (van Heugten, 2011). Research conducted by Maslach and Leiter (1997) found six environmental factors which can lead to burnout. These include values clashes or conflicts with respect to workplace missions, breakdown in the sense of community with work mates, insufficient rewards, lack of control, including rigid regulations and monitoring, unfair or disrespectful treatment, and work overload. The occurrence of these factors in caregivers' work experiences may explain why the HRC (2012) report found that burnout rates for caregivers is high. Scheid (2004) further suggested that lack of recognition of caregivers' emotional experiences, may eventually result

in burnout and this may be a contributing factor in the high staffing turnovers in many rest home facilities (HRC, 2012), due to the fact that it is difficult to find ways to maintain high levels of care unless there are considerable support mechanisms and support networks available to care workers. Fallon (2006) stated that burnout is a significant issue for this workforce and it is well past time that this is acknowledged by rest home managers and administrators.

Disenfranchised grief

Very few articles acknowledged that caregivers may need space in which to grieve a loss of a resident. While this gap is reflective of how little research has focused on this profession, it seems reasonable to expect that due to the multiple losses that caregivers must witness and experience, some form of internal grief work occurs.

Disenfranchised grief occurs when one experiences a loss that cannot be openly acknowledged or publicly mourned, or is not considered socially accepted (Wlodarczyk, 2010). As a concept, disenfranchised grief reflects societal discourses of grieving, specifically in regard to who should grieve for whom and for how long this grieving process should occur (Doka, 1989). For example, disenfranchised grief may occur if the relationship between the mourner and the deceased is not socially recognised (Doka, 1989; Parkes, 2006). In many cultures, including Pākehā (European New Zealanders) culture, acceptable grief or grieving is only associated with immediate biological family and fails to acknowledge wider relationships, such as friends, lovers, neighbours or individuals involved through wider social contacts and networks (Doka, 1989; Wlodarczyk 2010). By using the above definitions by Doka (1989), Parkes (2006) and Wlodarczyk (2010), caregivers can be understood as disenfranchised grievers as their relationships with residents does not fit within social expectations of a grieving individual. Furthermore, Fontana and Keene (2009) claimed that

because there is little social acknowledgement of these professionals or of the roles that they undertake, caregiver grief is not seen as legitimate. This disenfranchised grief is further compounded by the fact that older individuals within western societies are less valued and therefore grief over older peoples' deaths receives less social and community attention in general.

Caregivers dealing with other disenfranchised grievers

Given this definition of a disenfranchised griever, disenfranchisement may also be applied to the residents of rest home facilities. Doka (1989) suggested that older individuals often become disenfranchised grievers as they are not socially recognised or perceived as capable of understanding death or of grieving a loss due to their age. Doka (1989) continued by stating that older individuals are often left out of discussions and death rituals due to their age as families do not want to burden their older relative. This belief of not wanting to burden an older individual may contribute to some of the lack of death and EOL discussions.

Families as disenfranchised grievers

At the time of entering rest home facilities many family dynamics have changed significantly. Adult children may no longer emotionally recognise their parent due to changes in health status, emotional or cognitive abilities. Lloyd (2007, p.4) summarised this well by terming families' grief as the 'long goodbye', as cumulative losses mount (Cheng et al., 2010) and the roles of their loved one are taken away 'one piece at a time' (Lloyd, 2007, p.4). Cheng et al. (2010) noted that relationships with caregivers can be hindered because of this process, wherein many families may feel a sense of shame and anger about the situation, and that on many occasions' families are unsure where to direct these negative feelings.

Creating meaning

Meaning making

Being able to make meaning after a death is a significant aspect of adjusting and coming to terms with loss and trauma (Zilberfein, 1999). Meaning making is a critical issue for coping with death as it serves to maintain two aspects; our sense of self and our beliefs about how the world works (Davis & Nolen-Hoeksema, 2001). Death experiences can also create and maintain a sense of belonging for those that have provided care (Djivre et al., 2012). However, meaning making and a sense of belonging can be compromised during periods of loss and trauma (Davis & Nolen-Hoeksema, 2001). According to Davis and Nolen-Hoeksema (2001), when death is consistent with the world views of a group, the meaning making process is more straightforward and can begin immediately after the death. Examples are when a death is seen as predictable, the natural end of a long life, or is consistent with religious or philosophical principles about life and death. This is an important point to consider when exploring the death perspectives of caregivers. As Lloyd (2004) noted, older individuals are socially expected to die before the young, their death is viewed as a relatively natural event and therefore such losses may already make some sense. However, such social perceptions relating to age and acceptance of death have meant that that older individuals are presumed to be more accepting, more emotionally prepared, or less traumatised by the idea of death compared to younger individuals (Sidell, Katz & Komaromy, 2000) and as a result their concerns fail to be explored. This is also an example of the many contradictions with which caregivers negotiate, as highlighted here, there is potentially a belief within society that older individuals somehow know how to die or that death is acceptable in older age. Yet caregivers must work with individuals' who are scared to die or the dying process (Ohnsorge et al., 2012).

When meaning cannot be readily made after death, the griever must either revise their interpretation of loss to make it consistent with their worldviews or revise their worldviews to accommodate the loss (Davis & Nolen-Hoeksema, 2001). Durall (2011) found that when there was a conflict between the expectations of death and the reality of death, nursing staff found that grieving and the meaning making processes were harder. Durall (2011) further found that medical staff expressed sadness over failed medical interventions at the time of death, as this challenged their perceptions about their role or worldview. Given that caregivers have repeated exposure to death with little or no time to process the death of one resident before having to face another, and given that they are responsible for providing care for the living and the dying, it seems reasonable to assert that more exploration of this topic is needed.

Spirituality and meaning making

It has been suggested that spirituality may increase caregivers' ability to create positive meanings out of death experiences (Carroll, 2001). Lloyd (2007) found that caregivers with greater levels of spiritual transcendence and spiritual coping behaviours demonstrated lower levels of depression, decreased feelings of loss and higher levels of being able to create meaning out of the caregiver role. Furthermore, Davis and Nolen-Hoeksema (2001) found that spiritual beliefs provided a comforting explanation for events that could otherwise not be explained. This notion appears to have validity as according to results within this study, statements such as "I've seem things I can't explain" were a fairly common occurrence.

Doing dirty work

Caregiving is often framed as dirty work, literally and figuratively (Stacey, 2005) and is socially understood and viewed through one function; the handling of bodily waste products.

Indeed, Hughes (1962) found that society delegates dirty work to certain groups within society and in turn stigmatises individuals involved within these professions. Despite the fact that caregivers may not face overt discrimination as a result of their profession, Jervis (2001, p.94) suggested that there are subtle ways in which this profession has been distanced from the public gaze to help maintain the 'invisible' status of caregiving. Jervis (2001) suggested that caregivers are symbolically polluted by the tasks that they must perform and they are consequently tainted by this perception. This notion of symbolic pollution offers some insight in to why this profession has remained unrecognised and seen as lowly.

The notion of dirty work is made more complex by the fact that many caregivers actively recognise the dirtiness of their work but are still able to create positive working identities. This ability to create dignity and reward was achieved, as Ashford and Kreiner (1999) and Stacey (2005) found, through the belief that not everyone is capable or even willing to undertake the jobs that are conducted by caregivers. As Jervis (2001) and Stacey (2005) found, mastery of dirty jobs can be a determinant of positive self-identity and this is one way in which meaning can be created by caregivers. This notion of dignity in dirty work was echoed within this research as most participants noted that not all individuals can undertake this work. This ability to understand that caregiving is perceived as dirty work and still undertake these tasks displayed by caregivers is an undervalued and under-researched aspect of the caregiving industry even though it highlights a significant dimension of self-identification and self-worth work undertaken within this profession.

Whilst this highlights how a dominant negative social perspective can be reframed positively, it also demonstrates the tensions which caregivers must negotiate. It is conceivable that not all caregivers would be able to navigate this process and without support mechanisms,

feelings of being undervalued would remain high. Reasons such as the aforementioned may account for high staff turnover within the first year of work of caregivers.

Incontinence or the care of incontinence is one of the most symbolically and practically obvious forms of dirty work. It is also one of the ways in which existing power dynamics are maintained within this industry. Jervis (2001) found that caregivers were often scolded, at times in front of residents, over their perceived lack of good continence care. The issue of continence care and maintaining power dynamics was also highlighted within the HRC (2012) report where it was found that within some facilities, caregivers who were perceived to be using too many incontinence products would have to pay for these extra continence products from their personal wage. This example illuminates a considerable conflict in the expectations which caregivers must negotiate as they work, that conflict being between providing good care versus the cost of good care.

Gender and language

Gender influences patterns of care and is an overarching organising category for caregivers. It was not a central theme within interviews, however, and is therefore not a central focus of this thesis. There are many possible explanations for why the caregiving industry is predominately female and gender stereotypes play a significant role. Since much of the current research on gender and care focuses on informal care patterns, gender in relation to organised care work is a possible avenue for future research. For the purpose of this thesis, the literature search was confined to topics identified as being directly relevant to the findings, in particular the use of language to construct caring work.

Gendered expectations also significantly influence patterns of care (Lynch and Lyons, 2008) and care is often framed as 'women's work' (Hoffman & Mitchell, 1998, p.6). Aronson's

(1992) research, although about informal familial caregivers, raised some interesting points about the language used to frame care. It found that the care of the elderly is related to what are seen as womanly virtues, such as self-sacrifice and humility. Furthermore, self-descriptions of caregivers showed differences in key words that were used: female caregivers often used the term 'duty' or 'obligation', compared to their male counterparts who spoke of love in regard to providing care (Aronson, 1992, p.16).

Conclusion

This literature review has identified the main themes and gaps within current EOL care research. It is clear that there is a significant amount of research that identifies and examines some of the key tensions that EOL caregivers face, including the low paid, un-regulated, unacknowledged working conditions that exist for care workers, the emotional labour required, and the context of dirty work. Having identified these key themes, it is also clear that little is known about how caregivers negotiate these tensions, and about how they make meaning of these tensions and their EOL care work more generally.

In conclusion, the gaps identified in the literature highlight the need to know more about how care workers deal both emotionally and physically with EOL care. The next chapter outlines the methodological approach taken, methods, ethics and issues encountered while gathering data within this research project.

Chapter Three: Methods

Introduction

It has been established that caregivers are significantly involved in the EOL care of rest home residents; however, this involvement is underrepresented within current research and theorising. Whilst there is much theorising that attempts to explain and sociologically analyse experiences of dying (Howarth, 2007; Lloyd, 2004; McNamara, 2004; Mezey, Miller & Linton-Nelson, 1999), many of these theories focus on the dying individual and their family members to the exclusion of formal caregivers. What is more, little is explained about how death and dying is managed by caregivers, both physically and emotionally. This lack of interest may reflect a macro societal attitude toward care work that often undervalues it. This may have created a situation in which caregivers have become disenfranchised workers and ignored as potential research participants. Experiences of death and dying differ considerably globally, nationally, culturally and even within the same institutional care setting. Given that Aotearoa, like many other countries, has an ageing population; it is perhaps well past time that research began to focus on the individuals who help provide EOL care.

An interpretative perspective

The aim of this research is to investigate and explore how rest homes caregivers deal with meeting their own emotional and physical needs while attending to the EOL care of residents. A qualitative research approach is appropriate here because this study is within a field that has been largely underexplored. Furthermore, it is hoped that new ideas will be developed instead of testing narrow themes or sets of hypotheses.

My perspective for this research was interpretive as I wanted to be able to gather subjective accounts of how caregivers attended to the many dimensions of their work and develop themes and ideas from this data that could contribute to the development of theory (Liamputtong & Ezzy, 2005).

A grounded theory approach

From amongst the range of approaches that are appropriate from within an interpretative perspective, a grounded theory approach was adopted for this research, and this was done for several reasons. I identified a grounded theory approach as being the most appropriate strategy for achieving the study's aims of exploring how rest homes caregivers deal with meeting their own emotional and physical needs while attending to the EOL care of residents within their care. Grounded theory allows rich narratives to become an integral aspect of generating meaning (Glaser, 1992; Glaser & Strauss, 1967; Rennie, 2006). It enables key themes or indigenous typologies to be explored and understood, as well as enabling the significance of social actions such as pausing, laughing or subtle changes in the direction of discussion to be examined (Bernard & Ryan, 2010).What is more, grounded theory recognises the strength of complex social relationships not only throughout data but also across data, which allows social contexts to be explored (Bernard & Ryan, 2010).

Several other techniques of gathering data were initially considered, this included the technique of ethnography. It was initially thought that ethnography through participant observation might help highlight the complex environments and relationships in which caregivers must work (Labaree, 2002). However, after initial discussion it was thought that this methodological approach would give rise to considerable ethical difficulties. The first consideration needed to be for the relationship between the participants and the rest home residents. Questions arose about whether or not my presence would impinge upon the

relationship between participant and rest home resident. For example, would a participant hold back from discussing beliefs about appropriate EOL care in front of a resident or their family, for fear of then being seen to act out of keeping with ideal care provisions that they have been heard to promote. To explain further, a caregiver might feel considerable reluctance to reflect negatively on conduct and situations when they are able to be observed to be actively engaged in similar behaviours. Discussion surrounding how the researcher's presence might negatively impact on relationships in the workplace, such as caregiver relationships with rest home residents, families of residents, colleagues or their employer also identified the importance of not harming those relationships as a key consideration.

Furthermore, using ethnography would mean that consent networks would have had to expand significantly and I would have had to gain consent from numerous parties. Although research ethics require that consent must be obtained freely and must be informed (Tolich, 2010), given that this research is directed around EOL care not all residents would have been able to give consent for my presence. This would have meant that consent would have had to have been obtained from family members. It was thought that because death trajectories are difficult to predict (Ellershaw & Ward, 2003) and discussions pertaining to death within rest home settings occur in a rather ad hoc manner, some families may not always be aware of their loved one's condition. My presence might therefore be ill-timed or otherwise not welcome at this private time. It would appear that the decision not to employ ethnography for this particular research was probably wise as it was later found that recruitment of participants encountered many obstacles, and adding observation would have been highly likely to add to these challenges.

Survey questionnaires were yet another technique of generating data considered for this research. While this technique may help highlight emergent themes within a research

population group, the processes of reflection is not readily achieved nor are values or beliefs readily highlighted. Consequently, this means that assumptions about the research group may not be addressed or may even be promoted as a result of a lack of opportunity for the conversational un-packing of ideas. Unlike survey questionnaires, face to face interviews can reach beyond expectable responses. The interviewer is then able to examine not only content, but can discern subtle changes in voice and bodily reactions, and gain a sense of any emotional cues that the participant may exhibit.

Grounded theory originally emerged as a method in response to the tendency for research to only test existing grand theories or hypotheses. Grounded theory was first employed in the study of death and dying by Glaser and Strauss (1965) and is an appropriate method to employ where minimal research has been conducted.

Grounded theory is often used to help uncover basic social processes whilst highlighting integral social relationships and the contextual factors that affect individuals' lives (Strauss & Corbin, 1990). Grounded theory is inductively derived, meaning that themes gathered are data driven (Liamputtong & Ezzy, 2005). Because the analysis also occurs alongside the data gathering, and this method requires the researcher to constantly refer back to the data and across data as the interviewing and analysis proceed, reflexive considerations of fit, relevance, workability and modifiability of the direction of theorising occur throughout the research. Furthermore, as well as grounded theory being inductive it is also deductive, meaning that initial ideas produced from the data are tested back against new data (Hansen, 2009). This ensures that research conducted using grounded theory resonates and reflects the reality of individuals who share experiences of a social phenomenon or common culture (Hansen, 2009).

Another significant consideration that influenced the choice of this method is its capacity to incorporate relational ethics in its approach, as it is able to recognise connections between the researcher and participants and the communities in which they may share (Ellis, 2007).

Whilst open-mindedness continues to be a relevant consideration in grounded theory, recent revisions of the methodology more clearly recognise that researchers come with prior knowledge and experiences and that these may help in the development of the questions that research is aiming to address (Ellis, 2007). This resonated with me as a researcher and a caregiver; the experiences that I had shared or witnessed as a caregiver meant that I had a personal goal in undertaking this research, which was that I wanted it to make sense to caregivers, and contribute positively to the profile of caregivers within the care industry, and to the overall functioning of the care industry in its provision of EOL care.

Data gathering methods

Semi-structured interviews

Since much existing research does little to place caregivers within the scope of expert it was important that the approach chosen could help elicit events or details that the participant themselves thought to be significant. Therefore, subjective meanings and interpretations that individuals attached to their experiences needed to be able to be generated and explained by the individual themselves (Liamputtong & Ezzy, 2005). This is because semi-structured interviews enable both researcher and participant to co-construct data through the generation of dialog. As Baker stated 'if treated as "accounts", we can investigate the "sense-making work through which participants engage in explaining, attributing, justifying, describing and otherwise finding possible sense or orderliness in various events, people, places and courses

of action they talk about'" (2002, cited in Roulston, 2010, p.47). This resonates with the philosophy of grounded theory.

I took a semi-structured approach to questions, which were kept very broad to ensure a full exploration. To begin with, I thought that it was important to explore how caregivers deal emotionally and physically with EOL care practices and how their methods of coping impact on their motivations and ongoing capacity for this work. Whilst this is still the underlying aim of this research project, much of the data and discussions about findings refocused my attention to concentrate on refining my understanding of what was found within research: *The imagination of care: caregivers' perspectives on EOL care within rest homes.*

It was also hoped that semi-structured interviews would enable participants to openly reflect and discuss personal practice on a somewhat taboo topic. This meant that it was important to facilitate participants to talk in ways that gave clues as to how they associated meaning to their working lives. Given the sensitive nature of the subject, it was vital to ensure that participants would not feel intimidated by the data gathering process, and that they were neither restricted in what they could talk about, nor forced to talk about matters they did not wish to discuss. All these considerations were significant factors in deciding to use semi-structured interviews.

Since the aims of using grounded theory include the development of new explanatory theory, it was important that data generation would enable this. By using semi-structured interviews, the influence of pre-determined researcher ideas about the construction of the caregiving industry that might impact upon how participants narrate their making of meaning, can be limited. Whilst unstructured interviews would have been the most appropriate technique to reduce researcher influence through generated representations (Roulston, 2010), the downside of this technique is the likelihood that respondents may not talk about aspects that

the researcher is concerned with and the approach can be time consuming for the participants. It was important to ensure that interviews would not be too time consuming for the participants, who are busy in their jobs and therefore time poor. Another benefit of using semi-structured interviews is that these avoid a deductive approach and can be amended as new issues arise, which is a key consideration within grounded theory.

Selecting participants

The recruitment of potential participants was based mainly on employment status and geographic location. Firstly, participants had to have worked or be currently working as formal caregivers, essentially meaning that they had to have received or be receiving an income for providing care to individuals within a rest home setting. Secondly, potential participants needed to be currently residing and working within the Canterbury region. It was hoped that participants would be drawn from the wide spectrum that care occurs within, including rest homes which are privately funded, publicly funded, or provided specialised services such as dementia care.

Recruitment

Initial recruitment was undertaken by sending information packs (see appendix) to the managers of several rest homes from the Canterbury region; these rest homes were selected by using the website *finda.co.nz* to search for rest homes within the Canterbury region. The selection of these initial rest homes was ad hoc; they ranged from smaller rest homes to rest homes which are owned by large corporate organisations. The information packs included a covering letter to management that detailed the aims of the project and outlined how recruitment and interviewing would be conducted. Any managers who replied and who thought the research might be of interest to their staff were then asked to make the participant

information sheet accessible to staff. It was requested that the participant information sheets be located in a private but accessible location. This was requested to ensure that potential participants would be able to gather information about the research without feeling any sense of coercion, and to minimise any possible negative consequences within their workplace for potentially participating. Once a potential participant had decided that they might be interested in participating they were asked to make direct contact with the researcher.

Once a potential participant made contact, a participant information pack was sent to the potential participant's home address (see appendix). This pack contained more in-depth information about the research, including the aims of the research, and a list of prompt questions which was provided so that potential participants could begin to engage in some reflection around the broad topics that might be covered during the interview process. The prompt questions (see appendix) were designed to elicit discussion of both the content of the roles that caregivers carry out, as well as evoke discussion about the meanings that these individuals attach to those roles and actions. Some of the prompt questions were designed to invite caregivers to discuss contextual aspects of their role that they themselves felt needed attention. Questions such as, "What do you enjoy about the caregiving profession?" and "What are less satisfying aspects of your job?" were used in the hope that it would encourage caregivers to discuss tensions that they had experienced because of their roles. Questions were both factual and subjective in nature; factual questions pertained to specific aspects of their job, such as describing a normal shift. Subjective elements included explorations of social attitudes towards this profession and how caregivers frame death as good or bad. Furthermore, by using semi-structured interviews, generic information, such as work history could be gained as well as explicit information such as their professional experiences of EOL care and how this had impacted on them both physically and emotionally. Some resources that caregivers might wish to utilise in the event that the interview brought about any

emotional distress or negative feelings were also enclosed. This pack contained the caregiver consent form; it was requested that this form be signed before meeting for the interview.

Interview process

The interviews all began with a brief introduction of the researcher and the aims of the research. It was noted that at this point in the interviews all participants wanted to know how I had arrived at studying such a topic. Due to this interest, I felt it was appropriate to briefly discuss my own experiences of working as a formal caregiver. At this stage I would also talk about the interview process, reiterating that the interview would be recorded and explaining that this would enable me to concentrate on the content of discussion. I explained that there were no right or wrong answers to the questions that might be asked of them and that the interview was about their personal experience of being a caregiver, and about how experiences of EOL care had impacted on them both physically and emotionally.

I then stated that I would ask some prompt questions or might ask for them to further clarify a point or example if necessary, but that otherwise this interview would very much flow like a conversation. I would discuss the resources in the participant information sheet; these included the contact details of some free services within the community that they might wish to access in the event that the interview brought about any emotional distress or negative feelings. The right to withdraw at any stage was also discussed and I explained that if they wanted to ask any questions at any time they should feel free. I explained that they could ask for a break at any time. Finally, I checked that they understood all the information that had been discussed and asked if they had any questions. This is when I placed the audio recorder in an appropriate place, asked if they were ready and then pressed record.

All interviews began with the same generic questions pertaining to their experience as a caregiver. I believed these open ended type questions helped develop participant confidence because participants were able to easily answer these questions and the initial discussion quickly established that the interviewer was engaging in reflective listening. Reflective listening is an important aspect of interviewing, as it enables both clarifications of responses and acts as a form of encouragement for the participant (Bolstad, 2004). The respondents' commentaries varied considerably in length, with some going into great detail about their experiences, and explaining at length how they had conducted certain elements of their work. It was very rare that responses were one worded. Interviews varied in length, from approximately 47 minutes to 116 minutes.

At the conclusion of the interview I inquired into the participant's wellbeing and asked if there was anything else that they wanted to add. The participant was thanked for their time and the audio recorder was stopped.

Data analysis

Three participants were initially recruited to take part in the research and these interviews were conducted and transcribed by the researcher to help generate some of the initial concepts or open coding, which is the first level of abstraction in the analysis (Mathar, 2008). Some of these open codes included aspects of communication regarding EOL care within rest homes. Although existing literature does suggest that EOL communication gathering practices vary considerably, it was interesting to learn the extent of these practices. Participants' commentaries on how they dealt with death and dying were gathered under the conceptual heading of room for grief. It was notable that caregivers received minimal guidance on how they should or could manage or process any emotional feelings or distress. From this early analysis, the notion of room for grief became a significant focal point for

future interviews. This illustrates the grounded theory process in action; as data emerges and is analysed, future data gathering can pursue new directions indicated in that analysis. EOL had initially been identified as a code but after these interviews it became apparent that this was far too broad, and consequently this was divided into several codes, including EOL wishes, EOL priorities, and moral judgements about how to care for dying residents.

At the end of the first three interviews, all participants continued to engage in conversation after the audio recorder had been stopped. Whilst the topics of these conversations varied considerably, many further expanded upon their discussion of their cultural beliefs surrounding death and dying and how these did not always fit within rest home frameworks. From there, it was interesting to note how aware many of the caregivers were of many social attitudes that surround this profession. Social awareness had been an initial code; however, this was in relation to social attitudes towards death. Consequently, further codes were formed to more clearly reflect different kinds of social awareness. It was apparent that caregivers generally thought that current social attitudes towards their profession were mainly negative; many came across as feeling upset about the lack of respect that was shown to their residents and also toward themselves for the job that they do. Many noted that not all individuals are capable of doing this kind of work.

After leaving an interview, I wrote memos pertaining to the overall ideas, thoughts, and feelings encountered or observed during the interview. Memos were also a way by which any specific events, topics or new thoughts that may have been elicited were recorded to act as a reminder and help with analysis at a later date. After the interviews, the transcripts were typed out by the researcher, this is when another code was identified, that being nervous laughter.

After the first three interviews the process of open coding continued for each interview. Open coding is the process of generating initial concepts from data; this was achieved by reading and re-reading transcripts line by line and making notes in the margins. Dozens of codes were generated, which eventually combined into themes and categories. Questions to interrogate the data were constantly formulated, and these included questions asking what was missing in the texts, or what happened prior or after a certain emotion was expressed or a behaviour such as a laugh occurred. I endeavoured to identify if there was evidence of conflict, verbal contradictions, informal methods of control of expressions, and whether there was information about how people solved problems (Bernard & Ryan, 2010). Questions such as the aforementioned helped in beginning to unpack some of the complex social relationships that the participants negotiate as part of their working identity. It also began to help highlight the many social obligations that caregivers felt in regard to how EOL care should be conducted.

Significant quotes or important statements were also identified and labelled and this aided *in vivo coding*. In vivo coding is about identifying common phrases, words or silences and the context in which these occur in interviews (Corbin & Strauss, 2008). In vivo codes were collected under headings such as nervous laughter or a good death.

This process helped identify expressions or quotes that appeared to go together (Charmaz, 2006), and aided in the identification of emerging themes. More abstract ideas began to be developed through this extensive open coding. Abstract ideas led to new questions and provided direction for further interviews. The reflexive process encouraged and required continual checking of research fit, relevance and the workability of emergent ideas. Memos were also written during the analysis stage and were a significant tool throughout the research. This practice allowed me to keep track of ideas or feelings that I thought

participants had expressed or that I myself may have developed, and to reconsider those in light of later analysis.

As more interviews were conducted the same steps in the analytical approach were followed; transcripts were read and reread and comparisons between transcripts were made. Themes such as communication, family, good death, bad death, were identified and their potential linkages were cross analysed. Whilst this process was time consuming it was necessary to thoroughly examine the relationship of codes as a step toward generating and redeveloping more abstract codes Rigour, fit and applicability of evolving themes were constantly monitored. Situational maps began to be created to show these more abstract relationships; this is known as the process of axial coding (Charmaz, 2000). Axial coding is the development of linking between conceptual families or coding paradigms. Many of my initial thoughts or themes were moved under the headings of these more abstract ideas and relationship maps. At this stage literature also began to be included in analysis, what current theories could be applied or how was this research filling any potential gaps. Twenty two theme categories were initially identified.

As relationships between theoretical frameworks began to be more formalised, coding became more selective. Eventually the analysis and grouping of relationships between themes is expected to lead to the emergence of a core category. Underlying themes and their relationships can be seen to fit within this core category. At this point I was struggling to handle a considerable amount of information and several potential core categories were originally worked with. My core category at this stage was the culture of rest homes. I felt that this category did reflect and encompass the relationships between many of the codes emergent within analysis; however, whilst I felt that this core category may reflect how caregivers work within this industry I was unsure if it reflected how they emotionally and

physically coped with this work. Furthermore, this category seemed to relate more to the environment of their work and how this impacted their discourse, rather than to how they as individuals influenced the way in which they navigate EOL care.

At this point I presented some of my initial findings at a College of Arts post-graduate day. In many ways this helped crystallise my thoughts and allowed for the development of ideas that were more theoretical. It was during the preparation for this presentation that I realised theoretical saturation had occurred. Theoretical saturation occurs at the point at which data collection and analysis result in no new emergent themes occurring, and where further analysis of data and literature confirms rather than extends theorising. I realised that the theory of *the imagination of care* was responsive to my thesis question and offered a dynamic explanatory framework for understanding the working environment and the discourses which caregivers enlist to make their work meaningful.

Research considerations

Recruitment issues

After receiving ethical approval on June the 6th 2012, 15 information packages were sent out to rest homes within the Canterbury region. However, after some initial success with recruiting three participants there were few leads for more participants.

The lack of responses by potential participants soon became a topic of conversation between Ruth, Kate and me and at one particular meeting several things to help encourage participation were decided upon. Firstly, that I needed to further extend my potential participant network to include outer Canterbury and that I should amend my ethics application to include the technique of snowballing, so that the researcher's details might be more freely passed on to potentially interested individuals. It was also discussed that a more

personal approach may be required when approaching rest home managers, and that I should also follow up with rest home managers from whom I had not heard back.

Following this discussion, I sent out an email of introduction to managers of rest homes I had not yet approached. This email outlined who I was and the aims of this research. In this email, managers were asked to inform me if they were interested in more information being sent to them. This more personalised approach was far more successful; several rest home managers were fast to reply saying that I was welcome to send more information, and several participants were recruited from these rest homes.

An amendment to my ethics application to include the technique of snowballing was sent in on the 2nd of August, 2012 and was approved by the Human Ethics Committee on the 8th of August, 2012. The technique of snowballing also brought about some immediate results, with caregivers actively recruiting fellow caregivers to participate. I think that having caregivers act as advocates for this research effectively increased feelings of security and confidentiality for other potential participants.

Gatekeepers

Whilst some of the rest home managers were helpful, the notion of gatekeeping became a significant issue. Gatekeepers are people via whom researchers may gain access or entry in to a cultural group they are hoping to study, or by whom access can be prevented. Jupp (2006) suggested that gatekeepers play a fundamental part in research by both managing researchers' physical access to an organisation as well as influencing the degree of support the researcher is subsequently given by potential participants or other stakeholder individuals within these organisations. Jupp (2006) noted that gatekeepers are usually considered to hold a high degree of respect within a group. This was demonstrated by some managers actively

recruiting caregivers to participate and also by fellow caregivers encouraging participation. However, the place of gatekeepers highlights some potential issues of power dynamics or respect dynamics within the culture of some rest homes and specifically in regard to the relationships between rest home managers and caregivers. During the research interview, many of the participants were asked to express what they thought made a good rest home manager. Factors such as being hands on and knowing what it was like for caregivers were two of the most common positive qualities identified. Other qualities that participants identified as reflective of good managers were good communication skills, sound and up to date clinical skills and the ability to connect with residents as well as staff. All participants expressed that they felt generally happy with their current managers but all noted that they had had varying experiences with previous managers, including unhappy experiences were differences in care philosophies or practices had occurred. This alerted me to the possibility that complex concerns might have given rise to the gatekeeping issues that arose within this study. Whilst four more rest home managers came forward after the email of introduction and a short dialogue about the research had occurred, it is perhaps fair to assume that some managers may have had reputational concerns if caregivers spoke about their work. Managers may also have been concerned about protecting the identities of rest homes and rest home residents and about the extent to which this protection could be guaranteed. What is more, some rest home managers may have had to negotiate the appropriateness and reputational safety of this research with other stakeholders, such as boards of governors, and the potential negatives might have appeared to outweigh the possible gains.

Insider position

It was noted that many of the caregivers were relieved when I informed them that at the time of undertaking the research I was working as a caregiver and attending university part time. I

think that this established that I was able to relate to the social world in which they were involved, and perhaps suggested that I would be less inclined to be judgmental. As Ellis, Adams and Bochner (2010) noted, who we are and our past experiences significantly influence how we proceed when we conduct research. This also implies that my experiences should be subject to the same kind of analytic focus as those of the participants (Pitman, 2002). This insider-ness did bring about one dilemma. At the end of many of the interviews, participants often enquired about where I worked as a caregiver. This was not a question for which I had prepared myself. They had all openly discussed their work histories during the interviews but I was unsure about how much I should share with participants as I did not want to distract from their experiences and expertise. In the end, I stated the suburb in which this rest home is located and all seemed happy with this response.

Participant follow up

A follow up email inquiring into the participants' wellbeing and their experiences of the interview process, and whether there was anything that they wanted to add was sent out, usually within a week of the interview; only one participant responded. This participant stated that she had felt "cleansed" after the interview, stating that at times in the past she had felt very "heavy" about some of the emotions or experiences she had had as a caregiver. At the end of the interviews, when offered a copy of the transcripts only three participants had said they would like to receive this. All three no longer worked within the industry. I wondered if this reflected how work within this industry is conducted; it is managed but there is little room for reflectivity while actively engaged in practice.

The importance of confidentiality

Considering that this research dealt with potentially vulnerable individuals, including both rest home residents and caregivers, and also examined rest home practices, confidentiality was an important concern. For this reason no names of participants, rest homes, workers, or residents are mentioned in the thesis. Consent forms were kept securely locked or were pass worded protected in word documents and stored separately from transcripts so there was no possibility of matching these should documents be accessed by unauthorised people. Because snowballing was used as a technique of recruitment, there were instances were a participant might ask if I had interviewed someone that they knew or had referred. Whilst I felt gratitude that participating caregivers were encouraging others to partake, I realised that it would be unethical to reveal such information. I would reply that I could not answer that question but they were welcome to check with these individuals themselves. The technique of snowballing also meant that individuals would approach me with names of people whom they thought I should contact. I would thank them and hand them an information package and say that my details were listed and that it would be great if they could ask the potential participant to make contact with me. This was to avoid directly instigating contact with potential participants as this could have been perceived as a form of coercion.

Methodological reflections

Issues with recruitment

Recruitment of participants was considerably harder than I initially imagined it would be. I had thought that with much recent media attention being paid to the caring profession, rest home managers and caregivers would be eager to participate. However, on reflection media attention may have had the opposite effect. Managers and caregivers could have held

reserved views of my possible intentions, perhaps being protective of the culture that they worked within.

The method of using rest home managers as an access point for recruitment showed mixed success; of the managers that did not want to participate none offered a reason as to why. However, the ones that did participate were extremely forthcoming and actively encouraged participation by caregivers, with some even suggesting that this may help improve conditions within rest homes. It was interesting to note that participants who were referred by rest home managers demonstrated considerably less concern about potential workplace consequences compared to participants who had been recruited by snowballing.

Being an insider to both the caregiving world and the research world, perhaps my expectations about participation were too high. Expanding my contact networks in an attempt to recruit more participants resulted in my receiving some relevant critique of my methods from people with industry experience. Comments included that

- it was unlikely that caregivers would be given time off to attend an interview and the expectation that participants would come along during their own time may be somewhat limiting
- an hour long interview, which was the stated duration on the information sheet, may be too long (based on attendance at educational and up-skilling sessions)
- travel costs would be a major consideration for many participants since they are underpaid.

On further reflection I did not fully comprehend the extent of the invisible nature of this profession. My research, from the recruitment of participants through to the analysis of the interviews, has made me more aware of this. This invisibility both causes and is compounded

by lack of attention from researchers or open discussion about the reality of caregivers' working worlds. On reflection, however, the caregivers that I interviewed proved passionate about the work they do and noted the importance of the role they perform.

The research sample

In total nine interviews were conducted over a period of four months. Theoretical saturation was achieved by the ninth interview. Although grounded theory research is normally conducted with more participants, it was decided that in view of a core category having emerged, and due to the time constraints around Masters level research, and the complexity of grounded data analysis, this would be a sufficient number of participants.

The age of participants varied; most were in their 40s, the youngest interviewee was in her mid-20s and the oldest participant was in her 50s. Five out of the nine participants had had some form of nursing training. One was a registered nurse. Experience also varied from 26 years' experience to three years' experience, and the majority of participants had worked in the industry for over 10 years. Eight of the participants were female and one was male. Eight identified as New Zealanders, and within this group three identified as Māori and one identified as Samoan. The ninth interviewee identified as Filipino. Six out of the nine participants were currently working in the industry; two of the three that were not had had their workplace affected by the Canterbury earthquakes and one had just recently gone on maternity leave.

Conclusion

In conclusion, grounded theory was selected as an appropriate method for the research, given its aims. The kind of issues encountered with participant recruitment led to a gap between the initial group of interviews and the second lot of interviews which with hindsight helped to

progress the analysis and generate many initial findings and themes. It also meant that data analysis did not trail its gathering but took place concurrently. In the interests of time, some reviewing of the literature was explored in the interval between the first and the second sets of interviews, and more extensive reviewing took place after the identification of themes such as dirty work, emotional labour, and the distillation of the core category of the imagination of care. The idea of holding an insider position was also a significant consideration when deciding to undertake grounded theory as I was well aware that I wanted this research to reflect and resonate with caregivers' experiences, and grounded theorising is consistent with that aim. The research also saw me embark on an interesting personal journey from being a student/caregiver to developing an identity as a researcher. The next chapter outlines the main themes to emerge from the interviews.

Chapter Four: Findings

Introduction

Up to this point, this thesis has focused on a discussion of themes in the literature and has also explained the methodological approach used to investigate the thesis question. This chapter outlines some of the challenges faced by caregivers as part of their role. The chapter focusses on exploring participant discourses around their work, linking these discourses with literature where appropriate, to identify emergent themes. Themes within this chapter include communication, attachment, social attitudes, managing tensions, grief work and framing a death as good or bad.

Communication

Communication, within a rest home facility was highlighted as a significant issue by the caregivers interviewed. Whilst their experiences differed considerably, there was a common theme that communication or lack of flow of communication created workplace tension for many caregivers. Participants were particular concerned about lack of communication with respect to residents' wishes surrounding EOL care. The lack of communication pathways, or guidelines around how communication around caring for residents should involve caregivers, was also mentioned throughout the literature (Mathie et al., 2011; Shemmings, 1996; Siddell, Katz & Komaromy, 2000). Other researchers have noted that caregivers were often not included within gathering communication as they were not viewed as part of a resident's long term care plan (HRC, 2012; Froggatt, 2007). As Helen aptly pointed out, *We are the ones who have the most contact with them but I kinda feel that we are not always involved in the communication about what is happening.*

This tension surrounding the flow of communication and involvement of caregivers in care related discussions was further highlighted by Joy who began to describe a family meeting during which discussion was held regarding the welfare or wellbeing of a resident. These discussions may revolve around changes in condition or concerns held by family members. This is how she described who are involved and what perspectives are excluded.

> *You'll usually find the RN; you could have a doctor and all the other services that help look after the resident, the OT, physio ok, the only one you don't have brought in is the caregiver ok.*

She continued,

> *Caregivers are not invited to those but yip when something is brought up and they don't know about it they will go and check with one of the caregivers, I find it really hard to comprehend why; you know not one caregiver is invited into those meetings.*

The issue of communication was also raised by most of the participants in regard to dealing with the families of the residents for whom they care.

> *We have families come in and they are so in denial about what is going on, it's not gonna happen, it's not gonna happen, but it does and we talk to them tell them that this is what we deal with everyday* (Ali).

Communication and the resident

Many participants stated that for many residents they might be the only human contact during the day, and therefore in many respects they became their link to the outside world. One participant stated that she would often read letters from family members to residents, as she felt this was an important aspect of maintaining communication. Yet, despite being in a

potentially significant linking position, because the caregivers were excluded from important team and family discussions, they were unable to use this position to help keep the residents informed, or provide feedback from residents to people who were making care decisions.

Communication and EOL care

Despite obstacles, caregivers endeavoured to keep a continual flow of communication and they considered this to be significant even when care became distinctly EOL.

> *Keeping communication going with the family and the resident telling them what you are going to do. Mr or Mrs Hooper or Cooper telling them what you are doing and keeping that reassurance telling them that they are going to have a lot of different faces in and out of there so yet again you give reassurance by giving them introductions. You'll find a lot of residents who get to that stage who are on pumps on morphine or on lots of drugs are quite out of it so they don't know who you are but that doesn't matter, keep them up to date* (Joy).

Communication regarding EOL care and wishes were a noted area of mixed feelings and expectations. Many were unsure of organisational procedures relating to how EOL wishes were ascertained, stating that they thought this kind of information would be found in their case files.

> *Ah that's usually the manager's job, they would make sure that there was something in their file but it's usually written in their will. The manager usually deals with that one* (Mary).

Susan responded to how EOL wishes are obtained, by stating,

Ahhh . . . I guess it is discussed with management. I'm not that sure that it really does

occur that much, I mean I've never really had any wishes about end of life explicitly

told to me. I guess there are some common sense things when someone begins

palliative care.

She continued by stating,

I guess at times I've felt a bit in the dark as to what we are meant to actually do when

somebody begins palliative care.

When Helen discussed the transition to palliative care, she noted that in her experience caregivers were often not part of this discussion process, referring to palliative care transition decisions being made by management, doctors and occasionally families. She noted,

I guess in general there's not a moment where everybody is told so and so is on

palliative care as such. . . . Sometimes I've felt like it is a bit of a guessing game.

Kate noted,

It wouldn't be a bad thing to discuss, you know, not at the time when they first come

in, they know that they are not going to live forever and they know that they are going

to go through that process of dying and maybe they could have more input into it

then, not later when they can't express themselves.

It was interesting that many participants used terms such as *I guess* in reference to their

opinions about how EOL care communications were obtained, and this was interesting

because it perhaps indicated a tentativeness coming through in the way in which they phrased

their opinions. The rather ad hoc approach and attitude towards gathering EOL care

communications, was also found to be a theme in the literature (Lloyd, 2004; Siddell, Katz & Komaromy, 2000; Field & Cassel, 1997; Mathie et al., 2011; Shemmings, 1996).

Whilst most participants noted how important they felt these conversations were, it was notable that this importance was not associated with ideas about how their own job could be made easier, but rather with ensuring that residents' wishes were given due consideration.

Communication about residents' deaths with other residents

Communication flow after a resident's death was also highlighted as an issue by many of the caregivers. When asked about how other residents were informed, many participants felt that this was a delicate task. It appears that how this task was undertaken was often dependent on how the caregivers perceived the resident who had died would have wanted others to have been told. For example, some caregivers suggested that if the resident who had passed away was a private person the caregiver would usually not be as forthcoming with information. The flow of communication also depended on the emotional, physical and cognitive abilities of other residents. Many caregivers who had dementia care experience noted that whilst the other residents may not realise what had happened, they were able to pick up on the emotional state of the staff.

Practically all caregivers noted that most of the time surviving residents "just knew" someone had died. Many times when reviewing the transcripts I would hear that I had laughed at the point that this just knowing was being discussed. While they thought that residents often "just knew", many of the caregivers felt that there could be better management of how residents were informed. Some participants also noted that being aware of other residents' emotional state was a significant consideration for them in relation to what and how to communicate

about death. For example, they thought that for some other residents, the death of other residents may be too close to their own reality.

As Mary highlighted,

Generally they just click on (laughs). Yeah they just seem to know, you'd make sure they were ok and that could go on for several weeks because some of them had been good friends, being in the same home for so many years.

Communication and practices surrounding disclosures to staff

Communication flow to staff with respect to residents' deaths also varied considerably. There were many informal forms of communication between fellow caregivers. Text messages would often be the way in which other staff members who were not present at the time of a resident's death were informed.

A few staff had experienced turning up to work and not knowing that a death had just occurred. Whilst they all realised and understood that at times not everyone could be informed in a timely manner, some found it rather distressing to turn up to work and find out on the spot. As Susan noted, *I have come into work one day and was told when we were doing breakfast that Mrs so and so had passed away. It was a bit of a shock. I didn't have time to process it.*

Mark noted that not always being notified until their return to work meant that caregivers occasionally became very upset. Mark also described a death bed situation involving a resident in his care with whom he had become extremely close. He was visibly distressed when he discussed his experience.

"Mark. . . . Mark (pseudonym) where are you? I want to see you Mark. . . . where are you?" But yeah, it made me really sad that he was calling out my name and I couldn't be there. You know if they had rung me I would have gotten up at 3 or 4 in the morning. I volunteered to sit with people so wouldn't I? You know, it just really annoyed me.

Attachment

As the HRC (2012) report found, attachments are very real within the care industry and this attachment means that many caregivers will do 'extras', work after hours and 'this attachment to the elderly was seen to be exploited by funders' (HRC, 2012, p.19).

> *Sometimes you don't want to go home in case they pass away then, you don't like leaving them* (Mary).

The notion of caregiver attachment is a prevalent theme in the literature about practice in this sector (Mezey, Miller & Linton-Nelson, 1999; Morgan, 2005; Shemmings, 1996; Wilson & Daley, 1998) and was highlighted by all of the participants within this research. All of the caregivers spoke about emotionally connecting with the individuals for whom they cared. Terms of endearment such as "oldies" and "loved ones" were frequent in their discussions or descriptions of the residents.

This attachment can be a reciprocal matter as Sarah highlighted,

> *I had one lady, I wasn't working at that rest home anymore but she wanted to see me before she went so her family demanded that I be called and for her that was probably her only request that she wanted to see me before she slipped away. . . . Yeah so I got to see her and say goodbye and that's a privilege to know that you have cared for*

somebody and even though you had left they still wanted to see you. So I see looking

after the dying as a privilege.

Participants expressed some ambivalence about whether their attachments were legitimate, but at the same time they saw these as inevitable. Helen said, *I know that it is not really part of our job but still when you are involved with somebody on a daily basis you do form attachments.* Many of the participants made note of almost becoming like family in regard to how they viewed their relationships with the residents for whom they cared. As Kate noted, *you see them more than you see your family.*

Attachment and job satisfaction

The concept of attachment may also help us to understand why caregivers remain within this field of work: 'Carers themselves felt undervalued but emotionally rewarded for their work' (HRC, 2012, p.20). Many negative connotations are associated with care work and it has been shown that caregivers are aware of many of these negative social perceptions of the work they undertake. All of the participants within this study highlighted that the insufficient pay rates do not reflect or adequately compensate for the actual work undertaken and do not reflect the expertise found within this field. Despite that, the average amount of time spent as a caregiver within this research was 10 years. Sarah aptly stated, *if you're going to do caregiving you have to do it for love not money.*

All participants talked about the rewarding nature of this profession with many noting that they felt a sense of achievement and pride in the care that they provide. As Tina noted, *I've accepted that if I can do the best for them then I can't ask any more from myself.* Mark added,

Well, making a change, seeing a change in people's faces when you walk through the door, you know you are making a difference in their life . . . if one smiled at me and said hello well then I've done my job.

Attachment and protectiveness

Attachment also influenced how the participants worked, with many feeling a deep sense of commitment to ensuring that residents received the absolute best care that the caregivers were able to provide. Indeed many participants felt very protective of residents, echoing an idea that has been previously highlighted by Mezey, Miller and Linton-Nelson (1999). Kate said,

But I do go home and worry about it, like I shouldn't, but you wonder how the other staff are looking after them which I shouldn't they are just as qualified and they know but it's the little things. Like sometimes you know they like their pillow that side and they like to hold onto this. I like to do that but yeah you do have to sometimes go home and click off. But it's very hard.

In contrast, Mary told several stories of family members turning up only after the death of a resident, stating that at times the caregivers had thought that certain residents did not have family members alive until this happened. She said,

But yeah we had lots turn up after and that's very hard on the staff. Because staff do get attached and these are people that couldn't be bothered with them when they were alive and suddenly they're there to go through everything. It hurt to see that sort of thing.

Participants noted that their attachment to residents continued after residents were moved on to other facilities or had passed away. Many of the participants attended the funerals of

people for whom they had cared as they felt that this was an opportunity to pay their respect to the deceased individual and their family.

Social attitudes towards caregivers and dirty work

Perceived social attitudes towards caregivers were a noteworthy topic in the participants' discussions. Despite a strong sense of commitment, many felt that, generally speaking, society did not realistically know the work required by caregivers and that many attitudes held by the public were generally quite negative (HRC, 2012; Morgan, 2005). As Susan noted, *ah I guess we are an invisible profession. People only hear about the bad stories.*

Many spoke of a lack of social recognition or acknowledgement for the job they do.

> *Everybody expects more and you can't always give more, just for people to acknowledge what we do. People don't acknowledge what we do. I think that they think that we just sit and talk with them, make cups of tea (laughs)* Kate.

Susan noted, *I don't think it's a profession that's put out there, it's not like kids grow up and think yeah I'll be a caregiver.* Mary spent a considerable amount of time discussing the aspect of respect,

> *Because of the rate of pay for a start off, you've gotta be a certain type of person a lot of people cannot do what we have to do and it's the way you're looked at, you're not a RN, you're lower down the scale. So you're not respected the same way you should be.*

She continued,

No, no they have no idea what we actually do I think maybe some people think that it

is hard work but they have no idea to what extent that the job goes to, but no I don't

think society realistically knows how hard the job is. Sit around and drink coffee and

play bingo. Yeah whatever, somebody has to do it and these people deserve the right

to be looked after with the proper respect and dignity, yeah somebody has to do it

(laughs).

Many participants noted the fact that social attitudes toward caring work are reflected in how often attention is focused almost exclusively on the function of dealing with incontinence. *There's more to me than just wiping bums* (Mark). *It's just a dirty job and kiwis won't do it* (Tina).

Respect and dignity

Respect and dignity are two words that have significant meaning within rest home culture, and are often specifically mentioned in mission statements because dignity is closely linked or essential for the human spirit to function (Falkenberg, 2003). What is more, these two terms were used time and again within the participant interviews so it does appear that they are well embedded within rest home ethos. What makes these two words interesting is that while they were used in reference to the care of the residents, they seldom occurred when caregivers were referring to the work which they undertake. This may be because in some parts of their discussion caregivers used words that appear in official missions statements and care policy documents, but when they spoke of their caregiving work, they used relationship oriented words. So, when talking about the work they undertook, words such as respect and dignity were interchanged with notions of acknowledgement and thanks. As Susan noted,

I guess sometimes I feel quite unseen by management (nervous laugh). They don't always know what it is like for us. I mean their job isn't easy either but we are the frontline.

Helen added, *I guess I feel that caregivers are often forgotten, there's not a lot of thanks involved in this job.* Tina continued,

if people were paid more they would take more pride in their jobs. If the RNs and managers recognise the job that caregivers do that would lift the caregiver. But yeah it's a thankless job, the residents don't thank you, sometimes the families don't thank you until it's the end for all the hard work that person has done, but they had to wait until that person dies to get the thanks but not during the caring process.

Managing tensions

Many caregivers felt that their jobs were balancing acts. Many noted that they had considerable expectations to manage, because priorities of care differ considerably between many of the vested groups. Tensions and expectations can come from many sources including management, families, the residents as well as their own expectations of how EOL care should be undertaken. As Kate noted, *everybody expects more and you can't always give more.* This reiterates themes found in the literature that there are considerable tensions which caregivers must manage and that they can feel vulnerable when something goes wrong (HRC, 2012).

Time constraints

Many of the participants noted that on an average shift they would have been expected to allocate 30 minutes per resident. Whilst many of the participants felt very drawn to palliative care they also noted that palliative care was very time consuming and that they faced

considerable time constraints within their everyday work. In fact many spoke of giving more time to residents who were receiving palliative care even though this would often mean spending less time with other residents, as Helen noted,

> *I guess the sad thing is that for you to do extras you have to make cutbacks in other areas, so you may spend less time with other residents or you may spend less time with the resident who is dying. It's a balancing act, it's not easy. Especially when family are around, you have to keep them happy too which adds more stress to the situation.*

Mark spoke extensively about time restraints, noting that he had been spoken to by management several times, in several different workplaces, regarding his time management. He highlighted the tensions,

> *It's not a lot of time, you can't give them 100 per cent because you just don't have the time and there is many a day when you would just like to sit there and talk with them, reach out to them and show them that somebody actually cares. That time schedule is too short it's too rushed and that's what upsets them (residents) you know.*

Kate added,

> *Sometimes it does take you away from other residents, I must admit that you do spend more time with the palliative care residents than the more able residents but you've just got to sort of juggle your time but sometimes they don't get as much time as they should, cos the workload increases but you don't normally get extra staff on to manage it, so you've just got to make time.*

Later in his interview, Mark added how he thought EOL care could be improved within rest home facilities,

> *Spending time with them (sigh) and I'm not just talking about spending time washing them and cleaning their teeth and stuff like that but actually sitting down with them, holding their hand if that's what they like, but not over stepping your boundaries. Talking to them about what is going to happen I think that with talking comes acceptance and with acceptance it's easier to deal with, like when it comes time they should be able to talk about it, unless the person doesn't want to talk about it and that's fine too but you'll find that when the time gets closer that that person does want to talk and the thing is that caregivers aren't getting that opportunity to talk with them because they are on a time schedule. This has to be done, this has to be done, this has to be done, it's all about that, it's too rushed and I don't like it, the person is dying why not give them the time? They are not going to be here forever.*

The issue of time constraints highlights that the quality of care that is realistically able to be provided without caregivers making extensive additional personal efforts, falls below the currently recommended standards of care. These findings of differences between expectations, rhetoric, and realities begin to highlight the contradictory culture of rest home facilities.

Tensions and managing families

Many spoke about managing tensions surrounding families. Almost all participants spoke about how many families were struggling to understand that their family member was dying and that acceptance of this inevitability was not always an easy thing for families to achieve. This inability or un-willingness to accept the reality of death often resulted in situations

which were more stressful for those involved and many of the caregivers felt that because they are the majority of frontline workers they were often judged by families. As Susan stated,

> Sometimes the families get really angry at us, not that often but it does happen I guess acceptance is a tricky thing. Like I said sometimes families can make our job really hard they complain that we aren't doing enough. Ask why meds may have been stopped and that's not a caregiver's call but we are left in that position.

She continued by noting that at times she began to question herself and how she worked because of the tensions of trying to make everybody happy.

All participants had at one time questioned themselves in regard to how they managed their time, and what should be their priorities of care when a resident entered into the palliative phase. Questions or issues pertaining to where their time was spent, such as spending time with the living and not imminently dying had made many participants question themselves.

Helen commented that *it's more time consuming because you don't just have them to deal with but the families too which can take more time than the person themselves*.

Tensions with rest home managers

Kate also pointed out that tensions could arise when caregivers felt that their concerns were not listened to.

> I mean some managers' listen to you and others don't really care what you say, I think. I think I've had past managers, which would be going back about ten years that wouldn't listen to you and would think that you know nothing, they wouldn't take your interests to heart and family members they are different too, some do and some don't.

And according to Susan,

> *I guess sometimes I feel quite unseen by management (nervous laugh). They don't always know what it is like for us. I mean their job isn't easy either but we are front line.*

Challenges of EOL care

Caregiver safety

Only one participant spoke about feeling uncomfortably with some of the responsibilities that she was expected to carry. She said rather nervously,

> *Well I guess I've had to do tasks that I've never done before, I started work before my training and I was handing out medication and doing dressing. I mean it is all pretty straight forward but still. I guess I also don't get paid anymore when I have more responsibility either so that didn't make me always feel like doing more* (Tina).

Training

Many caregivers spoke about the fact that training is not always a given in many rest homes. Indeed, current literature reflects how meagre caregiver training provisions are (Fallon, 2006; HRC, 2012). Within this research only two of the participants expressed that they were satisfied with the amount of training that they had received. It was, however, unclear what kinds of training the participants would consider to be more satisfactory, or how often this training should occur.

By all accounts, the training that was received was very biologically and task orientated. There was no mention of the participants receiving any training in relation to spiritual or

emotional needs, either their own or in relation to residents in their care. Throughout all of the interviews, only two participants mentioned the place of policy. What was interesting was that the two participants who spoke about policy worked in rest homes that were closely affiliated with a hospice.

Emotional wellbeing and safety of caregivers

The literature review highlighted that little is known about how caregivers keep themselves emotional well and safe (HRC, 2012; Smith, Kerse & Parson, 2005) and that there are few support mechanisms currently in place to support these workers (Badkar, 2009; Badkar, Callister & Didham, 2009; HRC, 2012). In this research, responses to questions about how caregivers coped emotionally with their jobs were mixed. All noted that it was an emotionally tiring job, with most noting that they had developed a thicker skin so that they could emotionally disconnect when they went home. But a few commented that they would sometimes take their work home with them. As Kate stated,

> *Sometimes you go home but you worry, you worry that whoever is on [duty] won't do*
> *things how the resident likes it. I mean it's silly, they are just as qualified as you are*
> *but still you worry.*

Ali stated that she goes to the gym and *boxes it out* to help resolve any residual feelings.

Whilst most were encouraged to attend the funerals of the deceased, there were few participants who spoke of formal debriefing sessions where they could express any concerns or just say that they may have felt sad or upset. Many realised that they could, for example, receive counselling regarding a death if need be, but that they would have had to ask for these services. Kate spoke of an occasion when a formal debrief occurred.

I mean we had one resident who died and it did affect us all quite a lot. I mean we had a counsellor come in actually and it was actually quite good. I actually thought it would be a load of rubbish but when you actually went and you expressed your concerns—it wasn't a very nice death that the lady had—but like when we had a group discussion it was quite good for everyone and it was open to everyone.

She continued,

Sometimes when they die you think oh well and then ten minutes later you've got to get on with working and you don't stop and debrief, not really. It wouldn't hurt you to do, you actually see the residents much more than you see your family your with them every day so you do get attached and just because they are gone you just can't forget, you can't just keep motoring on, you've got to stop and think about it.

Grief work

Discussion surrounding how caregivers emotionally cope with EOL care and death was interesting with many referring to feeling upset but having to move on quickly as there was always someone else ready to start the process of EOL. Many participants became openly upset when having to discuss this moving on process, but they all stated that this was the nature of the job. Several techniques for coping with their own distress emerged. Some of these included physical exercise, attending funerals, and also having a strong belief system upon which they relied in times of need. Three participants referred to their own cultural beliefs and how these had helped them cope.

> *Caregiving is an emotional thing. So you would have to step away and it didn't matter how much you liked them. You had to step away otherwise it might destroy you. No not destroy you but bring you down* (Sarah).

Mark stated that in his culture caregivers

> *Celebrate death, we don't mourn a death it is a new beginning. I mean this is just a start for us anyway. I do believe that what you put out here you'll be rewarded up there.*

He continued with a story about one resident he was sitting with just before she died. He said,

> *I just sat with her stroking her arm saying it would be ok. She had big tears in her eyes and I thought, man this is hard, this is hard. I don't know if I can handle this anymore. But when she passed it was a release for me too as well as her.*

Many participants elaborated by explaining that they would try to do extras for the dying resident including just sitting with them or making sure that they had some of their favourite things around them. All noted that they would bring in fresh flowers for dying residents. Whilst it is a little unclear why participants undertook these extra tasks, these actions perhaps enabled them to provide a form of last rites and therefore helped in the participants' own grieving process. Their actions may also have been intended as a comfort or reassurance, therefore highlighting a mixture of self-care and altruism.

Grief work and the cultures of rest homes

Throughout interviews it became clear that the culture of rest homes impacted on how grief work was undertaken. As highlighted before, many rest homes do not provide formal or informal opportunities for debriefing, with the expectation that caregivers are to move on to

the next resident. Many of the participants appeared to believe that this was the nature of the industry but did also think that there was potential room to improve.

As Susan aptly stated,

> *We might talk at handover or with another workmate. I guess we have to move on quickly there are others that need our care. Sometimes I struggle with our lack of discussion especially if you weren't there when it happened.*

Joy spoke extensively about the culture of the current rest home, in which she worked.

> *A lot of families have had a loved one pass away and they still come in, they'll come in and maybe dress the flowers for another resident or bring in a plant or a picture for the actual ward itself and they will just come in to talk with staff I was quite blown away by that and you've got families that will come in and putter around in the garden outside you know. It's quite a family orientated place compared to others that haven't got that same environment, that atmosphere and the residents pick up on that.*

When asked if she felt that this helped her to cope in the aftermath of death she said,

> *Yes, seeing that the family are ok makes it easier. It makes you think yes we have done a good job because they seem to be doing ok. I'd like to die where I work.*

This was a powerful statement and there was a long pause afterwards as both the participant and researcher reflected on what had just been discussed.

Remembering and grief work

All participants were asked about what happens within the rest homes in which they worked after somebody has died, and whether there is some kind of memorial. Answers varied

considerably, from yes, there were types of memorial services at some facilities, to nothing being done. Whilst many of the participants spoke about their or others' attendance at funerals, many of them noted that enabling residents who wished to attend to these events involved a difficult process as this often required them to transport these residents within their own personal vehicles or swapping shifts to ensure they could attend. It is interesting that room to grieve for caregivers as well as other residents seems somewhat limited. Whilst, grief was not actively discouraged, it appears that spaces to grieve were also not created. Having said that, Joy noted that at her current place of work, there were spaces in which grief work could occur.

> *We have an office out front, so that's where the photos are displayed of whoever has passed away and it's not only for the family but for the staff as well to remember them. They stay up there as long as the family want them to stay up there but yeah everybody that passes away we always have a photo or a candle.*

Of the participants who were asked if they thought an in-house type memorial would be a good idea or not, many felt that it would be. As Helen noted,

> *It gives everybody a chance to remember. To grieve. Which is something I don't think is encouraged. Well it's not that it isn't encouraged, it's just, well it's just that it's almost ignored.*

Framing a death as good or bad

Many of the participants felt that their attitudes towards death were quite different to those in mainstream society, with many noting that death was often a welcomed release for the dying individual, their family and those who provided care for the dying. However, it was thought provoking that whilst they all did demonstrate an accepting attitude towards death and dying,

there were still many occasions were participates stated that taboo-ness associated with death and death discussions, even given the industry within which they worked.

A good death

There was considerable agreement among the participants about what a good death is, with many describing similar situations, behaviours or events. Many of these descriptions are similar to broad descriptions offered within the literature review such as, pain free, free from avoidable distress and suffering for patients, families and caregivers (Field & Cassell, 1997; Froggatt 2007; Lloyd 2004; Lloyd, White & Sutton 2011; Sidell, Katz & Komaromy 2000). It was interesting to note that nearly all participants did not struggle visibly in their descriptions of good deaths; however, this did occur when they described bad deaths as will be shown later. For many, it would appear that their own ability to make a death better was a significant contributing factor to how they worked and coped with EOL care. It is perhaps through a death being constructed as good that death could be understood as being more meaningful by the caregivers. When comparing the descriptions of a good or bad death, participants were more likely to use biological or medical terms when discussing a good death. This demonstrated that whilst caregiving is a somewhat intermediate profession, insofar as it is neither totally medically orientated nor totally spiritually orientated, discourse surrounding a good death is medically orientated. This perhaps demonstrates medical dominance in the dying industry.

Being pain-free and going to sleep and not waking up, or not even knowing the dying is going to happen, were constant themes in descriptions of a good death. These are interesting concepts as they highlight the bi-directional nature of caregiving. The participants work in an industry in which death is a relatively common experience, but because specific training regarding death management, including how they themselves might deal with death, is

lacking, common social attitudes such as it being preferable for dying people to not know that death is coming are amongst the resources they draw on in making sense of and assessing the contributions they make in their working lives.

Duration of EOL care

The duration of EOL was a significant indicator of a good death to all of the caregivers interviewed. Many felt that the longer somebody lingered the harder it was on the resident, the family and also the caregivers. Having family around, and the location of death, are also factors that were mentioned in reference to a good death.

As Susan stated,

> *I guess that they are pain-free, that they have their family around or somebody around. That they seem comfortable. Where I am now, we usually hold onto them until they die, which I think is nice. I'd hate to be shipped off somewhere, somewhere no one knows me, I don't know my surroundings (nervous laughter). Some have long left their bodies (nervous laughter). I guess it's more comforting to the family and in a sense the caregiver.*

Being there at the time of death

It would appear that being present at time of death helps to create a certain amount of meaning for caregivers. It enables them to process what has happened.

> *Good nursing staff who know when someone is in pain, making sure that resident is pain-free and not letting that resident not pass away in pain and keeping that resident clean not letting them lie in their own faeces or wet pad and turning them. You know*

doing those cares that stop their skin from breaking down its just quality nursing
(Joy).

Susan commented that, *well it's nice when they are still quite involved with normal rest home life for as long as possible.* When asked to further explain she continued with,

> *Um yeah. I guess what I'm saying they do get shut off in a sense. I guess it can make some of the other residents feel uncomfortable. It's like it's too close to their reality.*

Bad death

> *All I know is that families and death bring out the worst in people and nine times out of ten it's about the money* (Sarah).

> *A bad death is when they are not aware of what is going on. They are calling out for their family and they are not there. Yip, that's the hardest thing. They have things they want to say or peace to be made and the family is not there or else the family have things that they need to say but their loved one has passed away before they can even say them* (Joy).

> *When they are distressed. That's awful to watch (nervous laugh)* (Susan).

Many caregivers spoke about the amount of time spent in the final stages of dying and how these times were hard to manage. Several participants spoke about dramatic changes in residents' behaviours so much so that they felt that the resident had stopped being who they were long before they had actually died.

> *He became aggressive and a bit abusive (nervous laugh). He had always been a bit of a charmer so it wasn't nice to see him change so much. He made some us of scared of*

him. When he did die, he was for resuscitation (nervous laugh), so the ambulance was called and they worked on him for over 20 minutes. It was hard to watch (nervous laugh) everyone felt quite distressed, it just changes the atmosphere. We try to make their space as peaceful as possible but this changed everything.

Susan continued,

Sometimes we talk about how we wish someone would just go to sleep. Does that sound bad? (nervous laugh). I mean sometimes they linger for a long time and they are no longer themselves.

Conclusion

This chapter highlighted and discussed many of the main themes identified within participant interviews. Some links were made between theory identified within the literature review and how these are reflected in the everyday experiences of caregivers. Special attention was paid to communication practices which currently exist within rest home cultures; attachment of caregivers and the impact of social attitudes were also established as important themes. The complex environments in which caregivers operate were highlighted, including: managing tensions, the reality of EOL care, and how grief work is conducted. The notions of how death is framed were also considered and there was a discussion of how this relates to care practices. The next chapter discusses these findings in light of the thesis question and draws on more extensive associations with literature and theory.

Chapter Five: Discussion

Introduction

The previous findings chapter provided examples of quotations that captured and illustrated the experiences of caregivers as they endeavour to carry out their role in providing quality EOL care. Participants explained how they dealt with their tasks emotionally and physically. The analysis of that data aimed to gain a better insight into how the dilemmas and tensions of EOL care are negotiated by this particular work force. The findings highlight that support for quality of care in residential and nursing homes is in need of improvement, something that has also been noted by Ballard et al. (2001).

Most individuals living in rest home facilities will die in these locations (Hall, Longhurst & Higginson, 2009, p.411). Realities such as these highlight a significant issue or dilemma faced by many rest homes, which is whether or not a resident should be transferred to another facility when death is imminent. Rest homes have varying policies in regard to whether or not they will transfer a resident to a hospital facility as death nears. Many researchers have noted that this practice depends mostly upon a facility's resources and willingness to conduct this specialised care (HRC, 2012; Shemmings, 1996).

This discussion chapter focuses on the themes that arose throughout the analysis of the interviews, specifically how caregivers deal both emotionally and physically with the death and dying processes of the residents for whom they care. The themes that will be covered emerged inductively from the interview data. These include social attitudes towards caregivers and the residential care industry, the grief process of caregivers, and lingering in the dying process. This chapter will then go on to explore how some theories of social death begin to explain the considerable emotional labour and emotional intelligence that caregivers

have to demonstrate as part of their work. The concept of imagination of care (IOC) provides further insight into how participants negotiate residents' transitions from living to dying, and helps provide a framework for explaining how caregivers' past care experiences influence their current approaches to practice and provide tools that assist them in their efforts to care for individuals at the end of life. Rest homes operate in a bi-directional state, meaning that they are expected to deal with both living well and dying well. The fact that this care of the ageing and dying is done outside the public gaze means that little is known about caregivers' realities; rest homes are ideal social location for enabling society to avoid facing discomfort towards ageing, death and dying.

Social attitudes

It's just a dirty job (Tina).

The theme of caregiving being a socially devalued job arose continuously throughout the data gathering phase; it was discussed by all participants and was an identified theme within much of the literature (Badkar 2009; HRC, 2012; Gray & Heinsch, 2009; Labour/Green/Grey, 2010; Mezey, Miller & Linton-Nelson, 1999; Shemmings, 1996). This social devaluation is made more significant because socially, informal care patterns and expectations have moved from the domestic to the professional sphere, meaning that elder care is no longer considered the primary role of the family. Indeed, it has been identified that elderly parents no longer want to be a burden to their families, so that caring can now be undertaken within professional settings (Seymour, Kumar & Froggatt, 2005). This changing social expectation has been reflected in the rather dramatic increase and availability of rest home communities and is further reflected in the change in place of death, that being a move away from dying in private homes or hospital settings to dying in rest home facilities (Broad, Boyd and Connolly, 2011). However, with these shifts in social attitudes of care expectations and the location of

death, social attitudes that devalue caregiving and the individuals who undertake these roles still prevail.

It is currently unclear whether or not there is a widespread social belief that just anybody can provide care, but this may be the basis of many of the negative social attitudes faced by caregivers. What is clear, however, is that care expectations of caregivers have increased significantly, with more individuals who move into rest home facilities now having higher and more complex needs than ever before (Palliative Care Council of New Zealand (PCCNZ), 2013).

The analysis showed that the caregivers demonstrated high levels of awareness of many of these negative social stereotypes which continue to reproduce and maintain this role as devalued. As Mark stated,

> *There's more to me than wiping bums.*

The impact of social attitudes and finding positive self-identity

Much of the current research available on rest home care and caregivers states that caregivers are under qualified or that they do not remain within these jobs for long. These points are further compounded by the minimal, but yet damning media coverage regarding inadequate care or complaints of neglect that are made against this profession which are evident in headlines such as, *Crisis in our rest homes* (Wardle, 2012) and *More cases of elder abuse reported after earthquakes* (Mathewson, 2012). What is more, headline statements such as these do not offer much information about how caregivers are under qualified. For example, clarification regarding qualifications is not offered, meaning it is unclear if they are considered underqualified due to a lack of formal qualifications or due to a lack of professional experience in caring for the elderly and dying.

Whilst comments about qualifications and the labour market have some validity, they do not offer much information about the reality of caregivers' experiences of work, nor do they unpack the culture which rest homes currently operate within. The inability to engage with the experiential aspects of care work is perhaps best demonstrated by the lack of current policies governing the operation of rest homes in New Zealand. For example, there is currently no national policy governing staff ratios, and these are therefore determined by rest home managers. Caregiver registration is not currently required, and without policies governing qualification requirements, rest homes are failing to attract RNs because of the lack of clinical supports available to them within these facilities.

All participants within this study commented at length about the social devaluation and perception of this line of work as being dirty and that their work was seen by others, such as family, friends and wider society only through the function of dealing with bodily waste. Research by Ashford and Kreiner (1999), Jervis (2001) and Stacey (2005) regarding the mastery of socially perceived dirty jobs all noted that this mastery of doing dirty work can in turn become a key determinant in the creation of positive self-identity.

The development of a sense of mastery may be one means via which caregivers create meaning within their jobs. Indeed, in this research caregivers drew clear connections between being able to do dirty work and having the ability to create positive identities through the belief that not all individuals are capable of doing this type of work.

The grief process of caregivers

At some stage of their career, the participants within this study had felt a profound sense of loss after the death of a resident and this had impacted heavily on how they dealt with the

death and dying of other residents or how they perceived the meaning of death (Rando, 1986).

Whilst grieving processes occur within caregiver culture, such as attending funerals or sending text messages to other caregivers regarding the status of a resident, these grieving practices are done informally and with minimal recognition within rest home structures, rest home managers or academic researchers. Holley and Mast (2009, p.89) noted that 'caregiving is a complex psychological experience, and it is possible that the absence of grief from the conceptualisations of caregiver burden has delayed the development of a more accurate understanding of the full experience of caregivers'.

It was noted by many of the participants that they had felt frustrated and demonstrated indignant disbelief towards the practice of not clearly communicating when a resident has passed away. They expressed these responses both in relation to the lack of communication with themselves as caregivers but also in relation to the lack of communication with residents about the death of a fellow resident. Several of the participants suggested that the latter denied residents the space to grieve or be respected enough within rest home structures to be told. As Katz and Genevay (2002) proposed that the impact of loss is seldom recognised within the caring industry yet it these experiences help shape our patterns of care.

Attending funerals providing a form of closure

Many participants told stories of attending funerals of residents or helping surviving residents to attend these ceremonies. They felt that this attendance provided some closure for themselves and enabled them to show respect for the person who had passed away; they did not offer any explanations as to why they felt it was important for residents to attend. What this data suggests is that by caregivers informally attending funerals or assisting others to

attend, caregivers create cultural practices that are instituted and maintained by caregivers themselves. However, many of these informal practices receive minimal recognition from within rest home structures.

Grief and seeing caregivers as disenfranchised grievers

Informal, un-prescribed practices, such as the aforementioned, highlight the disenfranchised manner in which caregivers experience loss within their workplace. Their experiences of loss are seldom acknowledged within rest home communities and it appears that this lack of acknowledgement occurs so as to not disrupt the everyday practices of rest home cultures. Although rest homes do not deny death, the bi-directional manner in which they operate means that death is done rather covertly, perhaps in order not to upset other residents. Caregivers also appear to be cautious about openly displaying their participation in grief practices because without institutional and social recognition these practices remain under developed and therefore involved individuals are unsure of how they should act or react. There is minimal space and time to publicly mourn loss, especially in comparison to hospice settings where doing death is part of the underlying philosophy and a fundamental aspect of these institutions' cultural practices. The lack of mourning space and time for rest homes caregivers signals that caregivers are socially devalued because it is not socially acceptable or appropriate for these individuals to grieve in the workplace. As a concept, disenfranchised grief reflects societal discourse of grieving, specifically in regard to who should grieve for whom and for how long this grieving process should last (Doka, 1989). Disenfranchised grief also emphasises who should not be given the social right to grieve (Doka, 1989). Given this definition of disenfranchisement, it appears from the analysis that rest homes have created a culture which disenfranchises both caregivers and other residents' grief.

Dealing with other disenfranchised grievers

When they elaborated how other residents were informed of a death within rest home facilities, most participants confirmed that whilst death is conducted behind closed doors, many residents were aware of, or were able to interpret by the behaviour of caregivers that another resident was close to death or had just passed away. This "just knowing" of residents suggests that fellow residents are able to pick up on social actions surrounding death practices which occur within rest home facilities but that this ability is not overtly recognised and incorporated within rest home practices. According to Doka (1989), older individuals are often made to be disenfranchised grievers. This is due to common beliefs and practices surrounding informing people about a death. Beliefs about age and cognitive ability mean that much of society views older individuals as unable to cope with grief and loss. Not informing older persons is constructed as doing the older individual a favour because grief is assumed to be too burdensome for them (Doka, 1989). Although it is currently unclear why rest homes do not engage in telling residents of a death, beliefs about age and the inability to cope with death may offer some rationale behind current rest home practices around informing residents about deaths. Other factors resulting in this practice may include the belief that death is too close to residents' own reality and will be distressing. Rest home managers and some staff may also believe that residents do not form meaningful relationships with their fellow residents and therefore do not need to be informed. However, many participants noted the ability of fellow residents to see through the covert nature of death within these facilities. The attempts to shield them from knowing about other residents' deaths paradoxically demonstrate that in many instances residents are known not to be cognitively or emotionally impaired in their recognition or experiencing of grief and loss— otherwise they would not be perceived to need any such protection. In addition, participants

noted that debriefs about a death rarely occur, and that memorials take place in only some rest home facilities.

These points combine to suggest that caregivers are turned into what might be termed disenfranchised grievers via the EOL care processes in operation in the rest homes in which they work and in turn rest homes are embedded in a wider social context that is ambivalent towards EOL care. Furthermore, participants suggested that rest home managers have an overall expectation that caregivers must move on quickly as it is likely that another resident will soon need EOL care.

Imagination of care (IOC)

The imagination of care (IOC) is a way in which we can begin to understand how caregivers deal emotionally and physically with EOL care. The IOC provides a lens through which we can begin to understand and interpret death theories and how these relate to, and in some instances are challenged by, the everyday practices of caregivers.

Imagination is a phenomenon that many individuals may understand and have engaged in, and yet the concept is relatively hard to define or explain. Kearl (1989, p.472) summarised and theorised imagination by stating that 'what we think of a person influences how we will perceive them; how we perceive him influences how we will behave toward him; and how we behave toward him ultimately influences who he becomes'. Within this research, imagination related to care scenarios. The concept emerged inductively from the data relating to those care scenarios and developed into a theory to explain how imagination is used by caregivers to contradict to the notion of spoiled identities, their own and those of the people in their care. The imagination of care contradicts the notion of social death that is associated with aging, caring for the elderly and with death.

Kontos and Naglie (2007) and Hamington (2010) found that imagination allows individuals to transcend gaps between themselves and others. This is particularly significant in death, dying, and in relation to caring professions as it enables perspectives on care to move beyond ideas about efficiency and encourages care that is empathic to the individual, their situation and their needs. Kontos and Naglie (2007) further found that imagination in the care industry allows carers to bridge physical boundaries in that it allows individuals to put themselves in the shoes of the person for whom they are caring, thereby helping carers to understand the lives and circumstances of others regardless of personal, social or cultural differences. Others have noted that engaging in imagination allows for possible outcomes of caring actions to be hypothesised (Falkenberg, 2003; Hamington, 2010) and thus this can be a significant tool in deciding what actions or behaviours should be undertaken. A materialist medical perspective might suggest that death is surely the only outcome. Yet unlike many other professions within the medical arena, caregivers appear to not see death as failure but interpret failure or success dependent on the quality and consequences of care that is provided to the dying individual. For example, they take pride in the quality of their physical care of the dying or deceased's body, and the comfort this provides to the dying or deceased person's family.

Whilst few individuals can directly relate to the emotions or experiences of someone who is dying, by using their imagination caregivers are able to connect and reflect on situations where they may have felt overwhelming feelings of shame, frustration, fear or feelings of powerlessness. Therefore, the use of imagination allows caregivers to connect with their own past experiences or feelings in order to enable them to engage in empathic care practices.

How IOC arose

The theory of the IOC began to emerge when the phrase *prided myself on* was discovered to be a reoccurring theme of participant interviews. The term *prided myself* was often used

before or after a participant spoke about a role or task which was not considered a typical aspect of their work; tasks which were largely unrecognised or tasks which they felt are jobs which not all individuals are able to undertake, such as dealing with bodily waste or EOL cares. It became clear that many of the caregivers utilised their imagination when conducting their work. But while they utilised their imagination, it appeared that they, in many instances, employed this without consciously realising that they were doing so.

The imagination of care as a tool utilised by caregivers

Caregivers within this research noted that they felt it was important to form a picture of what a resident had been like prior to entering a rest home facility. Indeed, many recounted stories of residents they had looked after over the years, retelling stories of the people they had discovered the residents to have been before they entered the rest home facility, and in effect capturing a sense of the residents' identities through time. In many instances, the kinds of stories that the participants told could be seen to narratively clarify the residents' care expectations. Meaning that depending on previous life experiences, offers of help might not only be welcomed but expected to a certain degree. For example, many of the participants spoke about the diverse lives residents had led prior to entering the rest home facility at which they were working. Some residents had come from considerably privileged backgrounds, where receiving "help" was perhaps significantly easier to accept than for someone who had not previously experienced home help. The IOC practice did not take away from the identities which residents created for themselves within a rest home setting; instead, it appeared to act as a bridge that caregivers used to help gauge how residents' past experiences might influence their current expectations, to help direct caregivers' future practice. For example, in their interviews, the caregivers explained how, on meeting with a new resident, they would use prompts within the resident's bedrooms such as pictures,

ornaments or things that suggested an interest in a specific, place, time or activity. They would then utilise these prompts to help engage in conversation. As Susan noted,

> *You see a picture of a cat or a place; you ask them about it or somehow relate it to your own life. It helps take the attention away from why they are here. Why YOU are here. She continues you are entering into their house; you should get to know them.*

These observations were used to help engage in conversations and to help caregivers gain some sort of image of the identity of a new resident. That in turn was used to help create a context of care in the present but also to help create a context of care in the future when this resident would begin the dying process.

Sarah highlighted some of this process in action,

> *I loved them because it was a sense of history (in reference to caring as a job), it was the history and the era they lived in and they had so many stories to tell. One comes to mind about being pickled and smoked, that's all she did all day was smoke and drink brandy but behind that she had done many things. She had lived in India, she was a diplomat's wife, so she didn't have much to do, so from 2 o'clock onwards they would drink gin and play cards. I would imagine her sitting there in her beautiful clothes and what not and drinking gin with the other ladies and she had a wicked sense of humour.*

The participants' desire to establish a holistic picture of what a resident was like before they entered in to a rest home facility was highlighted well by Susan, even though it was in regard to funeral attendance,

I'm not sure if we avoid the topic or it's just that we all move on. Some of the caregivers attend the funeral, which I think is really nice, I don't. I don't like funerals but I guess for me it would be nice to hear more about that person, when they were young or to find out more about them, the person they were before they came to us.

In a sense, this practice of IOC enabled working identities to be created, that were then utilised in helping the caregivers gain knowledge of the person for whom they were caring in order to ensure that residents received the best possible care. To further highlight this point I will use the examples offered by participants, specifically the appropriateness of touch. Many of the participants spoke about touch or physical contact that extends beyond physical care, such as a hand squeeze or a kiss on the cheek. For some residents this was considered appropriate behaviour, whilst for others this would transcend carer/resident boundaries. What makes this interesting is that gestures like these often receive little attention at the time of arrival or when care plans are completed but can have a significant consequence in how care is delivered and received.

Determining the social, professional, and relational place of extensions from physical care to include emotional care was highlighted as a dilemma of care by participants. However, this dilemma signifies the importance of IOC in action and highlights a desire by caregivers to form and respond to a whole picture of the residents that are in their care. These points lead us to an important idea of investigation, that being the notion of social death.

Social death in relation to rest home cultures

Glaser and Strauss (1965) found that the family members of older individuals who were rest home residents or hospital patients often treated these relatives as if they were already dead or alive but perhaps not 'all here' (Sweeting & Gilhooly, 1997, p.93) or that 'their former

lives are all but ignored' (Kellear, 2007, p.221). Froggatt (2001) has defined social death as the cessation of an individual as an active agent in other people's lives, essentially meaning that while people may be biologically living they have minimal social connectedness to other individuals or other communities. This can result in people becoming effectively isolated and socially dead long before biological death occurs (Kellehear, 2007).

Rest homes operate in a somewhat invisible manner. Often people know little about their existence until they become directly involved with a rest home facility, either through themselves being admitted, the admission of a relative, or being employed by a rest home. Consequently, there is little knowledge within much of society about everyday practices in these environments. Coupled with this lack of general knowledge about everyday practices in these environments, is the fact that entering into a rest home facility usually follows other considerable losses, such as, possible loss of independence, family, friends and health status. Many rest homes advertise that they are a community that accommodates all needs. Yet, in effect moving into a rest home can separate and socially isolate residents from long established social connections that they had prior to moving into this facility, meaning that life may become insular as opportunities to maintain social connectedness diminish (Field & Cassel, 1997).

Kalish (1968, p.254) divided the concept of social death into two sub categories; these are self-perceived social death and other-perceived social death. Self-perceived social death is described to occur when an individual accepts the notion that they are as 'good as dead'. Other-perceived social death refers to the feelings of other individuals and their belief that this individual no longer resembles the person they formally were, and in many respects are for all purposes dead or non-existent. This may occur to some degree for caregivers during the time when they experience a resident to be lingering, which is when the dying phase takes

a considerable time; some participants indicated that at this point residents are not always recognisable to caregivers.

Social death in many ways may highlight the experiences of both the new rest home resident and of their family members on entering and remaining in a rest home facility. Although social death commonly refers to no longer being actively involved in wider community participation or disengaging from previous social roles and obligations long before physical or biological death, this study has the potential to highlight a way in which this theory is resisted by caregivers.

Caregivers working to counter social death within rest home facilities

Many of the participants spoke about their belief and need to continue caring for residents until they died within the rest home facilities. This desire to provide continuous care highlights a significant contradiction between the findings of this research and the expectation found in the literature that social death occurs when residents enter rest homes, since it seems more likely based on this analysis that caregivers work to counter social death from occurring. Caregivers within this study illustrated on numerous occasions that they acted as a bridge between a body that had been deemed void by society, to an individual who had a past. The caregivers' efforts to provide this bridge were significant in maintaining who the residents were now, during the dying phase.

Throughout participant interviews, many spoke about the rites and rituals that they brought to their work, providing examples that highlighted this bridging between caregivers and the dying resident and showed how they ensured residents remained alive within their social context. These examples included tasks such as sitting with residents during the dying phase, reading letters or cards from loved ones, still introducing new individuals, such as doctors or

palliative care specialists, and letting the dying resident know what was happening. Many participants spoke about how they would hover around a dying resident's bedroom, ensuring that any extras, such as a favourite possession were put in pride of place or fresh flowers were taken care of.

On only a few occasions did participants speak of how a resident was no longer socially active within the rest home facility. In many respects it appears that caregivers felt that residents were still very much involved due to their own continued involvement with them. This is a significant avenue to highlight the very tangible attachments that are formed between caregivers and residents for whom they care.

Counteracting social death by caregivers is highlighted within the data of this research as many participants noted that they struggled with processing a death if they were not present at the time of death. Susan highlighted this well,

> *I came into work one day and was told when we were doing breakfast that Mrs So and So had passed away. It was a bit of a shock. I guess I didn't have time to process it. Her death was sudden though.* She continued, *sometimes I struggle with our lack of discussion. Especially if you weren't there when it happened.*

The idea of social death became more evident once a resident was transferred to another facility in their final phase of the dying process. This is when the notion of social death became relevant to caregivers.

Many participants spoke about the continual worry they had about the welfare of a resident even after they had been moved to another facility. This worry was based on the belief that residents would only be seen and understood by new care staff in relation to the condition in which they had turned up. Consequently, there would be little time to form reciprocal or even

one sided caregiver to resident attachments. This timing would then hinder new staff in imagining what this person had been like before now, meaning that the new care providers may not be able to imagine the manner in which this person would like to be cared for and the manner in which they would like to die.

> *Sometimes you wonder how so and so is. Some caregivers I work with might go and visit or you may hear through the grapevine. We are always looking through the death notices (laughs).* Helen

This highlights an interesting point as caregivers interpreted that a shift to hospital facility care would become a premature return to social death because the caregiver would not be there to provide their IOC practices and care ethics. What is more, they were unable to provide the rites that they had imagined would be significant to the individual who is dying or has died. During the data collection many of the participants spoke about times when they had not been present at a death and how they had an underlying need to be told about the conditions and context in which this death occurred. The explanation for the participants' need to understand what had occurred during the process of death for a resident who was no longer in their care, lay in the importance of such knowledge for making sense of the dying person's continuous social identity as they moved toward death. This was identified by participants as a significant contributor to their own coming to terms with the death.

Indeed, many participants commented on their strong personal desire to *be there* for a resident's death or *keep them (within the facility) until they die*. It is likely that these comments reflect a belief about being able through their eyes to help complete a resident's death journey, thus helping to creating meaning in death, which has been identified as a significant factor in working with and processing death. Without knowledge of the ending of

a resident's journey, the continuity of care that participants had previously provided, supported by their imagination, came to an abrupt and disturbing end.

These comments and beliefs far exceeded the researcher's initial thoughts regarding how caregivers might process and create meaning within their work. This discovery of the IOC and related expectations that caregivers place on themselves significantly advances understanding of the complex context in which they work.

The significance of care relationships

On many occasions the participants noted that the relationships and attachments that they formed with residents were different from relationships that they formed outside of the rest home environment. They further commented that while these relationships do not meet socially constructed versions of reciprocating relationships, this did not decrease their desire to form strong connections with residents. They cited the strength of these connections with residents as being critical to performing their job well and being a source of considerable job satisfaction. Indeed, many participants liked to imagine what residents were like before entering into a rest home facility thus in many respects assessing how a person may have contributed to society and what made them unique, and then using this imagined social biography to help create a relationship which would then be used to help engage in care practice.

Imagining a social biography is an interesting practice technique as aging individuals are often perceived socially as no longer contributing or only contributing minimally to society and because of this are perceived socially as unable to maintain reciprocal or establish new relationships. Caregivers, however, look beyond these socially accepted perceptions of reciprocity to form meaningful relationships with the individuals for whom they care.

It is currently unclear why the meaningful relationships between caregivers and residents are often dismissed by rest home management or by families as insignificant. There are some suggestions about power dynamics and that power imbalances may lead to stresses or the disintegration of care relationships (Mezey, Miller & Linton-Nelson, 1999; Shemmings, 1996). Power imbalances seem less likely to occur between residents and caregivers. It seems more likely that power balances between caregivers and families, rest home managers, policy makers, and governments will constrain caring patterns and behaviours of caregivers.

Care relationships and comparisons with other research

Bogdan and Taylor (1989) explored the relationship between carers and individuals with severe disability. They found that although society had deemed these individuals who had severe disabilities to be unable to have or maintain reciprocating relationships, their carers believed otherwise (Bogdan & Taylor, 1989). Indeed, they found that individuals with severe disabilities offered many qualities that are required to form attachments, such as having and displaying a unique sense of self through their behaviours or actions.

This is a relevant finding because many of the negative stereotypes or social perceptions of the ageing and dying have similarities with perceptions of individuals with severe disability, such as not contributing to society, and being unable to have meaningful lives. However, Bogdan and Taylor's (1989) study highlighted that through the use of imagination, carers are able to identify unique qualities that these individuals offer and carers are therefore able to create meaningful attachments. What is more, this study further highlighted that imagination work creates a considerable amount of emotional satisfaction for the people providing care.

What is the imagination of care?

Essentially the IOC is a tool which appears to be used already by caregivers. It is the outcome of the caregivers' ability and self-imposed need to create a full picture of a resident for whom they are caring. The IOC enables caregivers to provide reflexive care that is attuned to the resident's needs and wants when the resident is physically, psychologically, or structurally prevented from being fully able to directly express those needs and wants. Prompts in the resident's room, such as photos or ornaments, and stories that are shared as a result of these prompts help create a life biography for this resident. This allows caregivers to create a care plan within their imagination that is not only person centred but in many respects history centred. Subsequently caregivers are able to imagine how they feel a resident may or may not want to be cared for as it allows a form of checking that their IOC beliefs fit with the person whom they are caring for. As needs change, the IOC assists the caregiver to attune to those changing needs.

Once identified as an explanatory theory, nuances in the use of imagination became even more apparent in regard to how EOL care was processed by the participants. As highlighted by Joy, *If I look after you like that then I hope that someone can look after me like that. That is how I have always done it.* This statement identified the belief in a "forward paid" relational interchange, whereby the participants will, in the future when they themselves are in need of care, be similarly cared for in reciprocating relationships with their own future caregivers; it is essentially a role reversal in perspective taking.

The notion and practice of the IOC by caregivers fundamentally works to resist the theory of the social death of residents within rest home facilities.

Imagination of care in action

As discussed earlier in this thesis, communication practices surrounding obtaining EOL wishes are currently limited within the rest home industry. This lack of clear practice guidelines can continue due to the fact that there are few legal requirements governing how EOL wishes should be obtained or discussed by rest home administrators. When information is gathered it is not always successfully filtered through to the individuals who have the most contact with residents, in this case caregivers. Susan noted this, *Well, information is not always filtered.* She continued, *It's weird but with some residents you can kind of imagine what they would want*.

At this point it should be noted that on a few occasions the participants spoke about having to revisit their initial thoughts about what constituted appropriate care for a particular resident in a more extensive way than the adjustments to changing needs already identified above. This revisiting of previous care practices was discussed only on a few occasions, mainly in regard to when a resident had lingered in the dying phase for a considerable amount of time and had, in participants' words, become quite different and unfamiliar to the person they had been when they initially starting caring for them.

When coupled with the fact that training for caregivers is meagre, the lack of guidelines around the obtaining of EOL care wishes leaves considerable gaps in how the ideal of good EOL care is delivered in reality. Indeed, this is where the IOC may be considered relevant.

Imagination of care bridging the gap

The practice of IOC bridges a significant gap between literature and practice, because to date there has been little research done into the processes involved when a dying individual and the person caring for them are treated as passive within the systems in which they exist. As

discussed earlier, society often associates both the aged and those who care for them as spoiled and soiled identities, and, whilst perhaps not as apparent, rest home cultures through many of their current practices dismiss many of the techniques or care ethics that caregivers themselves bring to the caring experience.

The IOC process may be a way in which caregivers and residents create a new relationship and power dynamic, working to counter the passive terms on which their roles would otherwise be constructed within this rest home system. This active countering can be seen when, for example, residents engage in telling stories and when they give signs of appreciation or show discomfort to caregivers in relation to care practices.

Imagination and EOL care

Without apparently knowingly setting out to talk about how they have engaged with their imagination in practice, many of the participants within this study spoke about this practice when discussing death.

When you have worked with someone for a long time you just know what they would like, or would want to happen (Mark).

Ah I guess I've never really spoken to a resident about how they will die or what will really happen after. But with some residents you can kind of imagine what they would want (Susan).

Helen added, *I guess I use my past experiences with them as a guide, think about their stories of who they were before they arrived here to help guide how I operate.*

In relation to caregivers' own death

At some stage of the interview process almost all participants spoke about their own deaths. This was somewhat surprising as I had not expected that this would come up in the interviews. However, this openness towards discussing death may be explained by the nature of the work that these individuals undertake. It was interesting to note that whilst there was this openness towards death many participants still identified the socially perceived taboo-ness of talking about death.

It is likely that providing care for dying rest home residents had sparked these thoughts about their own deaths and that being able to explore thoughts about the manner in which they hoped to die also influenced their current practices by assisting the IOC. Both processes, the sparking of thoughts about their own deaths, and the use of these thoughts to enhance care were reflected in the narratives of the participants, and they seemed to occur in a reciprocal relationship. As Kate noted, *I just have never wanted to die alone. That's part of the reason I will just sit with them at the end.*

Joy further added,

> *Treat them like your family because yip one day you are going to be elderly too, you know. I'd like to think that somebody will come in and look after me the same way that I have looked after all these others.*

Hamington (2010) highlighted that there is a connection between past experiences and how someone may adapt to a new situation guided by these past experiences or feelings. However, within my research the participants moved beyond past experiences and drew on the future to consider how to act in the present when they spoke about the reality of their own deaths, and

how contemplating their own deaths had significantly impacted on how they worked as caregivers.

For all those who spoke about their own death, the use of imagination had significantly influenced their own practice in terms of their EOL care for the rest home residents for whom they cared. Many of the participants spoke about the significance of imagining their own death and how this had alerted them to the importance of location and familiarity, which realisation they then endeavoured to incorporate in practice. As Ali illustrated, *I guess for me I'd want to be somewhere where I kind of knew that the people caring for me actually knew me.*

It is also possible that previous experiences of the deaths of people similarity in age, gender or similar cultural backgrounds were incorporated into at least some participants' own death bed thoughts. Throughout the analysis, references pertaining to attending the death bed of a close relative, such as a parent, were used as a way of highlighting how they felt caring should be carried out. Although the participants were recreating a familiar relationship, however, comments which overtly likened residents to parents or residents to themselves were rarely made. Throughout much of the literature, many research projects have found that similarities, including demographic similarities, between participants and people who have died were a precursor to thinking about the manner in which participants wanted their own dying process to occur. Whilst participants in this research did not make many references to similarities between themselves and residents for whom they cared during the dying process, on several occasions participants identified that similarities between a resident and caregiver could be a reason why some other caregivers were unable to do palliative care. They noted that for some caregivers, the dying experiences of residents were likely to be too close to their own realities. Helen demonstrated this point well when she said, *Just after my dad died I*

couldn't do palliative care, it was just too difficult. It was unclear whether the caregivers identified as likely to struggle with caring for the dying were themselves unwell or more similar in age to the rest home residents, or were currently or recently involved in looking after a relative who was in the dying process.

What much of this discussion highlights is the idea of attachment and reciprocation. Caregivers demonstrated awareness that society does not view the relationships that they have with residents as meeting normal social expectations of reciprocation. However, participants also appeared to believe that, while reciprocation was different in a caregiver-resident relationship compared to a relationship formed outside of these facilities, by providing good care now they would perhaps be rewarded when they themselves began the dying process.

Comparisons with other research

Despite an intensive literature search, only two articles were identified that discussed how participants used some form of imagination to engage in care practices. However, one of these, an article by Bogdan and Taylor (1989), did not discuss death practices. The authors of the other article, Wiese et al. (2010), explored issues raised by staff about the current status of EOL care of people with intellectual disabilities living in community supported accommodation. What this study highlighted was, that whilst staff were committed to the provision of EOL care, they often relied on previous experience to gauge practice and participants mentioned their use of imagination. For example, one participant mentioned that if they imagined that they were caring for their brother this would ensure that this individual was provided with quality care (Wiese et al., 2010, p.576).

Although mentioning the use of imagination, the focus of this article was predominantly on the care of those left behind after death, for instance, bereavement care support for peers and care workers. Overall, the literature review showed little evidence of exploration and understanding about how individuals who provide EOL care manage both emotionally and physically.

There are considerable similarities between these two fields of EOL care for older persons and EOL care for persons with intellectual disabilities, and they each provide multiple services to service users and their families. Organisations involved in each of these two fields of care can be seen to engage in a form of social control by providing a space in which mainstream society may have limited contact with these individuals, and both fields employ a work force that is largely unrecognised, unregulated and under researched.

The discovery of the use of imagination in both settings provides support for the notion that caregivers' lack of specific medical and EOL training and support has meant that they must incorporate their imagination to provide EOL care which is supportive of the individuals in their care. Hamington (2010, p.682) suggested that as members of society we will generally not participate in actions that we perceive as futile, and similarly we do not undertake caring actions that we do not imagine to have a high probability of success. This is relevant in terms of the thesis argument given that in many situations of rest home care, death is imminent and irreversible. With this in mind caregivers must move beyond this notion of physical material futility to continue in their caring. This highlights that whilst death may be the only perceivable outcome, the imagination of providing care to achieve a death that can be understood as experientially good versus bad may be a key consideration in maintaining caregivers' engagement with their role.

Rest home cultures which disempower

It has been shown that rest homes provide a context in which life and death occur simultaneously (Froggatt, 2001), and care practices co-exist. However, whilst this may not be the intention of rest home operators, rest homes are settings where many cultural practices largely disempower the caregiver work force.

This was clearly highlighted when participants spoke about paper work. As Sarah noted,

> *You have to write facts, you have to write 'I suspect' or write 'this is what happened'. I know that you have to watch your language and how you describe how something happened".* She continued, *yeah because it's a legal document and I know that there have been incidents where these notes have been used in court. I've noticed from when I started, to now, the paper work is overboard with the audit system the way it is, but yeah that's about it, it's all about paper work.*

The importance placed on the use of language was identified within several interviews. The participants identified that they must use words such as "appears" or "seems" when writing reports or progress notes. Words such as these will offer some legal protection, but they also disempower caregivers by highlighting that these individuals are not considered experts within their fields. While this is not the base of an argument about whether or not caregivers are experts, it should be recognised that these individuals offer some expertise in the care industry and their disempowerment is propelled by the fact that caregivers are not considered part of residents' long term care plan

Audits

It was interesting that the process of auditing was only mentioned by three participants. However, they all emphasised how stressful audits of care practices were. What was interesting was that while they recognised the importance of having checking procedures, the three participants felt that these checks were somewhat superficial in nature. For instance, they all felt that a considerable amount of time was spent checking paperwork, and whilst none argued that this was not a significant avenue for auditing, they noted that little or no time was spent checking the wellbeing or happiness of the residents and care staff alike. When questioned about the amount of time that auditors spent with caregivers, and the extent of input auditors sought from caregivers, all participants replied that this was minimal and managers typically selected only a few caregivers to speak with auditors. These concerns about the thoroughness of audits echoed issues raised by Labour/Green/Grey, (2010) who found that the relationship between facilities and auditors was often inappropriate because facilities can choose which auditor is to conduct the audit.

It may also be relevant to the current discussion to note that the auditing process is currently undertaken by the Hospitality Association, rather than by health authorities, highlighting the somewhat perplexing manner in which this industry is currently organised and regulated.

Conclusion

This chapter has focused on how caregivers deal emotionally and physically with providing EOL care. It is clear that caregivers must work and negotiate a complex environment in which many tensions exist. The key theoretical contribution is that it is also evident that they draw on what has been called an IOC as a tool to navigate successfully. As they negotiate this complex environment using their imagination of care, they are countering many aspects of

the notion that rest homes are a site of social death because they interpret their interaction as a way keeping rest home residents socially connected and therefore contributing to society and therefore the IOC is a theoretical development within the EOL field. This theory offers opportunities for further research and theoretical development with implications for policy.

The next chapter discusses these opportunities for further investigation and considers the thesis more broadly in terms of its contribution to EOL debates.

Chapter Six: Conclusion

Introduction

The cultures of rest homes are essentially bi-directional providing a space in which life and death occur concurrently. Current academic debates presume that the way care homes operate fosters social death through their EOL practices and that in turn marks them as a place through which society is able to deny death. I did not find that rest homes deny that death occurs within this space; however, their practices regarding death do need some further consideration. Firstly, further consideration is needed of the needs and concerns of those who die within these spaces, and also the individuals who provide care.

Caregivers had considerably high levels of self-awareness and this is a fundamental quality or capacity that maintained them within this line of work. They were aware of the many negative social stereotypes which surround this work, most notably the fact that it is considered by most members of society to be lowly and dirty. However, it was interesting to find that many felt a sense of accomplishment and pride in the fact that they were able to provide a service which they were aware few other individuals would be able to perform.

Cultures of rest homes

As discussed earlier, rest homes operate in a bi-directional manner, in that they provide the social space to live well and die well simultaneously. While Falkenberg (2003) noted that institutional structures can hinder and foster natural caring, based on this research, it is my belief that rest home cultures do not deny death but death is undertaken in a rather covert manner. It is hidden from other residents and currently there seems little in place to assist with grieving or coming to terms with loss for surviving residents and staff alike. There is a

lack of support for coming to terms not only with the losses and accompanying feelings that caregivers or residents may experience due to a death of a fellow resident, but also a lack of support to deal with the losses which have precipitated an older individual entering into a rest home facility in the first place.

It could be suggested that rest homes provide a culture of death and loss silence; they are a convenient way in which society can ignore the ageing and dying processes and there seems little set in place in regard to achieving more adequate communication processes. Lack of adequate communication and a culture of silence occur on many levels within rest home facilities. For instance, when an individual is admitted to a rest home facility, little if any information is gathered about how this individual would like, or believes that they would like, their dying process to be undertaken. If any information is gathered, this is seldom filtered through to the caregivers, who undertake the daily cares of the residents and consequently form attachments with the resident, and could therefore gain important insights from such information.

This culture of silence can be seen again when a resident dies. Some caregivers identified that they had created informal communication pathways regarding deaths of residents with other caregivers, via telephone or text message. Many stated that they had a significant need to gather information on a death if they were not present at the time, but this was not always possible, especially if death occurred in another facility. Few mentioned debriefing sessions, but these were provided in a rather ad hoc manner. This practice of silence around information about the death of a residence was also evident in how other residents were informed, or not informed, of a death.

I am not suggesting that it is always appropriate to inform every single caregiver or resident of a death; however, the need for improved information was an identified theme within the analysis, and such information was noted to help create meaning around death and dying.

Caregivers

Caregivers within this project demonstrated high levels of self-awareness regarding the mainly negative attitudes held within society regarding caring for the elderly, ageing and dying. The belief within society that these workers are underqualified needs further consideration, specifically, there is a need for clarity on what is meant by "qualifications" and how lack of qualification is being assessed. Although it may be the case that there is a lack of formal, nationally recognised qualifications within this field, the place of formal qualifications is but the very tip of the iceberg of our current lack of understanding of what makes some caregivers leave, while others remain engaged in their work and find considerable satisfaction and reward.

At the beginning of this research, a question was posed around why not more caregivers are qualified through a national organisation. The answer is simple: To gain qualifications, caregivers must undertake these during their own time, mainly at their own cost, and having more qualifications is not recognised in increased levels of pay. Qualifications are expensive and unrecognised by their employers. It would seem that these circumstances make gaining qualifications difficult for caregivers in terms of time, money and motivation.

The challenges surrounding training also highlight some significant issues about the recognition and acknowledgement that caregivers receive. It is my belief that many caregivers hold a substantial amount of expertise that is simply not recognised or acknowledged, neither within rest home culture nor by wider society.

This lack of recognition, coupled with the lack of communication flow within rest homes has created many informal ways in which caregivers operate and negotiate the environment in which they work. This has already been highlighted in the informal practice of informing other caregivers about the death of a resident. Yet another way in which this is highlighted is by the attachments which are formed between caregivers and residents. Whilst this behavioural pattern has been recognised within some literature, this is mainly in regard to this practice being cautioned against (HRC, 2012; Mezey, Miller & Linton-Nelson, 1999; Shemmings, 1996). However, attachment forming is a significant step in creating the IOC, which caregivers employ in their efforts to counteract the lack of practical recognition and acknowledgement of the importance of providing care that resonates with how residents would like their dying process to occur. This suggests attachments play a positive part in end of life care relationships that warrant more nuanced attention, rather than blanket cautionary warnings. The results of my research echo the conclusion of other authors that caregiving is maintained by the goodwill of caregivers (HRC, 2012; Shemmings, 1996).

What do caregivers want?

There was a strong sense that caregivers wanted to be better acknowledged for the roles that they perform and the tensions they must work within and they felt that this acknowledgment needed to come not only from rest home managers and from families of the individuals that they care for but also from wider society. Many of the jobs that caregivers perform are what others would label to be extras, and these jobs are not necessarily recognised as part of care routines by managers. Yet in the eyes of caregivers these are essential to providing quality care. These jobs can be as simple as holding hands, reading a letter from a loved one or even bringing a pet in to visit. These are examples of essential, albeit non-medical, tasks to maintain quality of dying. Although they may interfere with strict timeframes that have been

identified as required for physical cares, they help create meaning in caregivers' work and provide for emotional wellbeing of residents.

Many of the participants felt that more EOL communication needed to occur so that the wishes of the individuals who are dying could be incorporated into caregiving and so that people would be more likely to die in a manner they chose. However, as an exploratory study, the scope of this investigation was limited in investigating how this better communication might occur.

As far as training was concerned, many participants recognised that there is room for more training but their views about what kinds of training were required were mixed. It was evident that the participants thought that caregivers should become more involved in the direction of educational training and that they should be recognised as expert advisors on what training they needed. Despite this it was unclear from the findings how caregiver uptake of training might be increased, apart from increasing incentives, such as increasing wages to acknowledge training.

Participants' own thoughts about death, dying and EOL care

Most of the participants were able to freely discuss thoughts about how they themselves would like their dying process to occur. Thinking about their own deaths had helped create meaning in their roles as EOL care providers. The discussion and narration about their own deaths, coupled with the imagination narration of a resident's life had, it seems, helped create informal yet effective guidelines and moral values to adhere to.

All noted that death is a natural event but that the taboo-ness of death has created many boundaries in achieving a death which is understood as good by various involved individuals.

Feelings were somewhat divided over whether or not they felt that rest homes did indeed act as a "home away from home" to residents.

Death silence

There is a culture of death silence within rest homes and this starts as soon as individuals enter rest home facilities. There are no current requirements regarding the gathering of EOL communication from residents, families, or paid caregivers during the admission process, while living in rest homes, or during the dying process. Nor are there requirements, and often there are not even guidelines, about how a resident's death should be communicated about with caregivers and other residents. There was a clear understanding by participants that the privacy of residents and their families must be respected, but at the same time, the participants' processing of a death was easier when information about the death was made available to them. Only two participants stated that some grief practices were part of the culture of the rest homes in which they currently worked; this involved having a memorial photo within the office or reception area. Most of the other participants had seldom come across such grief supportive practices in their years of experience.

Gaps in current research

Currently there are considerable gaps in research regarding caregivers, but more specifically in regard to how caregivers function and process the work they undertake. What is more, there is an apparent lack of research that moves beyond the descriptive and links caregivers' experiences with theories of death and dying. This is disappointing considering that more research within this field may create strong links between the realities of death and dying and the theories relating to this subject.

Implications for practice

It was found that the caregivers within this study felt that there was a considerable need to recognise caregivers as part of the long term care plan of the residents for whom they cared. Many felt that the ability to contribute to these plans would help enhance the status of caregivers and also the quality of EOL care for residents.

Implications in policy

Serious consideration should be given to the meagre amount of policy that currently exists in the aged care arena. It is true that caregiving and rest homes run on the good will of the caregivers and other support staff who work there. As mentioned earlier, current projections about the need for aged care and the availability of caregivers to meet these needs will soon not match, if this mismatch has not already occurred. This problem is compounded by the fact that caregivers are also an aging population, with many set to retire in the next 20 years. It has been found that rest homes are failing to attract RNs due to the lack of clinical support. With respect to gender balance, apart from the pay rates and gendered perceptions of care, little is currently known about why rest homes are failing to attract male and younger caregivers. Questions should be asked regarding the current lack of policy, not only externally derived government or regulatory policy, but internal rest home policy that is decided upon by rest home management. This criticism does not apply to all rest home managers, and is not made without recognition of financial and other resource constraints, but notwithstanding such obstacles, issues such as staffing levels need to be addressed and palliative care strategies should become a core consideration in care plans. The interplay of multiple stake holders with financial and political interests, are relevant to this topic. Investigating these interests and their impacts fell, outside the scope of the current study, however.

Implications for future research

There is considerable room for more research into the death practices of caregivers and rest homes alike. Researchers and even political parties (as shown in the Caring Counts, 2011 report) have become interested in the aged sector. Although this increasing interest is more focussed on meeting the needs of the aged, it seems a natural progression that more research will need to be conducted regarding the individuals who provide this care. This has also been observed by Age Concern and this organisation has instigated a campaign to increase dignity for caregivers and by the historic court case win by Kristine Bartlett a caregiver against her former employer in regard to equal pay.

This research brought about many personal changes for me as a student, as I moved away from my personal experience of "being" a caregiver to that of a researcher. This, I believe, also meant that using a grounded theory perspective worked well within this research. The overall notion that with grounded theory findings must resonate with the participant group was a driving force in pushing this research further and perhaps helps explain why the transition from interested party, in this instance a caregiver, to a researcher did not occur until late within the study process.

The ageing process, and therefore also the dying process, have become more relevant to society due to the fact that we live in an ageing society. Some research has begun to emerge regarding the manner in which rest homes function but thus far this has done little to highlight the everyday realities and complex processes that caregivers must work within and negotiate.

The lack of interest in research into caregiving practices to date may provide some explanation for some of the obstacles that presented early on in my research, including some

of the issues experienced while trying to recruit participants. Initially, I approached rest home managers to act as a form of gatekeepers to help recruit caregivers to participate. This was met with mixed results; some rest home managers were very supportive but due to the overall lack of response using this method, recruitment was changed to use snowballing. I cannot explain with any degree of certainty why my initial approach of using rest home managers as gatekeepers was unsuccessful, but can hypothesise that lack of previous research exposure may have meant that many managers may have been cautious of the intentions of this research.

Conclusion

I started this thesis with personal insight that brought death and dying to my attention, specifically where and how do older New Zealander's go to die. As I researched more, my question clarified to how do caregivers manage the tensions associated with working in this secluded area of care especially with residents in EOL care phase. I developed the idea of the imagination of care to help articulate how that may be done. IOC may act as a new way in which EOL care is understood and contextualised. What it also achieves is that it highlights the complex systems and processes which caregivers must engage in to perform EOL care but also enable this care to remain emotionally and physically safe for themselves and those they are responsible for.

Caregivers have stories to share, good, bad, sad and funny, but the main point is that they have a considerable amount of expertise in their field of work and it is well past time were these stories are heard.

Appendix 1.1

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CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

PARTICIPANTS REQUIRED

Understanding the death and dying process of rest home residents: a caregivers perspective

Are you interested in participating in a research project about the role of caregivers, specifically how you manage the death and dying process of residents?

This research is part of a Maters Research project, and will involve a face to face interview which will take approximately one hour and will be at a time convenient to you. If you feel that you may be interested in this research please take one of these sheets so that you may contact the researcher on the details below and more information will be sent out to you.

This research is strictly confidential and you have the right to withdraw at any stage without penalty.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee.

Thank you for your time, I look forward to hearing from you.

Researcher
Shannon Swann
Phone: 021 02772126

Potential discussion topics
- Attitudes of caregivers to the death and dying process of residents within rest home settings.
- How caregivers manage both physically and emotionally when a resident is dying or has died.
- What caregivers consider a 'good death'.
- What caregivers feel their role is during the dying process.
- How does the dying process impact care?
- What are the priorities of care when a resident is dying?

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee.

Thank you for your time, I look forward to hearing from you.

Researcher
Shannon Swann
Email: spp22@uclive.ac.nz
Phone: 021 02772126

Supervisors
Dr Ruth McManus   Associate Professor Kate van Heugten
Email:ruth.mcmanus@canterbury.ac.nz   **Email:**kate.vanheugten@canterbury.ac.nz
Phone:364 2987 ext. 3046   **Phone:** 364 2987 ext.3230.

Potential topics
- Attitudes of caregivers to the death and dying process of residents within rest home settings.
- How caregivers manage both physically and emotionally when a resident is dying or has died.
- What caregivers consider to be a 'good death'.
- What caregivers feel their role is during the dying process.
- How does the dying process impact care?
- What are the priorities of care when a resident is dying?

Potential resources
- The Salvation Army Oasis Centre
  126 Bealy ave
  Ph 365 9659
- Lifeline
  Ph 0800 543 354
- Service and Food Workers Union Nga Ringa Tota
  Ph 0800 864 661

2

Appendix 1.2

College of Arts
School of Social and Political Sciences
Tel: +64 3 364 2899, Fax: + 64 364 2414
Web site: http://www.saps.canterbury.ac.nz/

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CHRISTCHURCH NEW ZEALAND

The death & dying process of rest home residents: a caregiver's perspective.
Information sheet

Dear Participant,

You have been invited to participate in research, which will explore the role of caregivers, specifically, how caregivers manage the death and dying process of residents within their care. Your professional insight into the role of care giving, specifically how you have dealt with death and dying professionally and how this has influenced your professional practice is of great interest to this project. You will be asked to attend one, face to face interview. It is estimated, that the interview will take one hour, the interview will take place at a time convenient to you, at the University of Canterbury campus or alternative venue if desired. The interview will be audio recorded so that the researcher can better listen to what you are saying instead of concentrating on writing notes. This discussion will then be typed out; this word document can then be sent out to you if you wish to review what has been said. The interviews will follow a somewhat unstructured format, as this will allow us to focus on your individual experience. A list of potential topics can be found at the bottom of this letter, these topics have been placed here so that you may begin to reflect on your experiences of dealing with death and dying.

It is not the intention of the researcher to cause offence but because we will be discussing death and dying and professional practice emotional distress or moral/cultural offence may occur. The researcher will endeavour to minimise this potential but if you feel that you may wish to speak to someone regarding issues covered, a list of potential contacts has been placed at the bottom of this sheet.

Your confidentiality is an important aspect of this project, information gathered will be kept in a secure filling cabinet at the University of Canterbury and electronic data will be protected by password and encryption. Your identity will be protected by using pseudonyms, any identifying information such as other caregivers' or residents' names that you offer within the interview will also be protected within the study. The researcher and her two supervisors are the only individuals who will see any of the original information gathered; however, the anonymous thesis verson will become a public document. You have the right to withdraw without penalty from this project at any stage; all information including your contact details will be destroyed and will not appear within the research.

As a researcher, I am interested in this subject as I have worked as a caregiver for several years and feel that more insight is needed, not only in how death and dying is dealt with, but also to highlight the significant role that caregivers contribute to society.

If you feel that you are interested in participating, please contact the researcher on the phone or email address below. If you have any questions, comments or concerns please feel free to contact the researcher or her supervisors as we are endeavouring to make this an enjoyable and safe experience.

1

Appendix 1.3

College of Arts
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CHRISTCHURCH NEW ZEALAND

Consent Form
Understanding the death and dying process of rest home residents: a caregivers perspective

I have read and understood the description of the above named project. On this basis, I agree to participate in the project.

I understand that the information I provide will be used in the completion of a MA thesis and article will be submitted to journal. This will mean that the information I provide will be published and be available to the public. However, my identity or any other identifying information given at any time will be kept strictly confidential. I understand that my privacy will be carefully protected and that any personal data relating to me will be kept in a locked and secure location.

I understand that I may withdraw from this project without penalty at any stage, this includes the withdrawal of any information that I have provided.

Your participation is greatly appreciated, if you have any questions, comments or concerns please feel free to contact either the researcher or her two supervisors at the details below.

Researcher: Shannon Swann
Email: spp22@uclive.ac.nz
Phone: 021 02772126

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Kate van Heugten
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ph 364 2987 ext.3230.

Name: (please print)

Signature:

Date:

1

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