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**End-of-life care for elderly within aged residential care
facilities:
Views and perceptions from their next-of-kin**

A thesis presented in partial fulfilment of the
requirements for the degree of

Master of Science
with an
Endorsement in Health Psychology

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New Zealand.

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Dedication

To my family, best friends and Beau, with love.

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To my parents, thank you for everything. I could not have got through this year, let alone the last four years, without the phone calls, the words of encouragement, money (and more money), all the hugs, food parcels and the countless other things that you both did, which were never taken for granted or will ever be forgotten. I couldn't have done it without either of you. Thank you.

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Abstract

By 2051, the number of people aged 65 and over will account for 1.33 million of New Zealand's population (Statistics New Zealand, 2006). This has created attention as to what current practices and facilities are available to this cohort of New Zealand's population, and what more we can do to make sure we provide adequate services. Limited literature provides insight into what takes place within aged-residential care (ARC) facilities during end-of-life (EoL), especially within New Zealand, even though approximately 40% of those aged 85 and above in New Zealand do already die in ARC facilities (Gibb, 2014). This project investigates the experiences and perceptions of EoL care for elderly within ARC facilities, from the perspective of their next-of-kin (NoK)/family member. Eleven NoK/family members who experienced the passing of their elderly relative within an ARC facility, were recruited as participants. The study used a qualitative method with semi-structured interviews. The interviews were then transcribed, and analysed using thematic analysis on Dedoose, a web-based application, to draw themes from the data. Questions were kept broad and open, so that participants would be able to relay their story as openly as possible without interruptions. The findings are presented under ten major themes which includes; the occurrence of a 'crisis' for their elderly relative, the responsibility and adjustment to the role of NoK, changes in the elderly relative's personality, the effort and kindness experienced within the ARC facility, reflection of the conversations participants had with their elderly relative, the multi-dimensional effect of pain, the process of letting go and

anticipatory grief, expectations of the 'good death', the influence family has on the experience of being the responsible NoK/family member, and the participants experience of grief while managing the funeral. The interpretation of the results highlighted the extended period that is considered to be EoL and its care within an ARC facility, as opposed to only the last few days before death. This research enables an insight of what entails EoL care within the environment of the ARC facility, as well as allowing the NoK/family member to share the story of their experience.

Preface

I am at work, standing by the nurse's station in the hospital wing of the ARC facility in Gisborne, New Zealand, where I was working as a physiotherapy aide. I've been told that *Jean* is now under palliative care and no longer requires her daily physiotherapy sessions. I have spent the last six months nearly every day for at least 20 minutes with *Jean* helping her move and stretch her limbs which were now no longer under her control, she had motor neuron disease. During those sessions, we would talk. She would tell me about how she was feeling and her frustrations with her disease. She had told me personal details of her life, all about her adopted children; I would get regular updates on them. She told me all about her husband, how they first met, their life together, what he did and how he had died. She told me all about her life, her first job, her jobs following that. How she was originally from Scotland, still having a bit of the accent to prove it. I'll never forget *Jean's* face when she said to me one day, "I don't feel like myself today, I don't feel like myself anymore at all". I realised then how much she was suffering both mentally, physically and emotionally. And now this woman who I had built this relationship with, who had shared so much with me was dying and her palliative care meant that no visitors were allowed. In the end I didn't get to say goodbye to *Jean*, she died a few days later, and to this day I still think of her often.

This was the moment that grabbed me. I knew I wanted to find out more; what had gone on behind that closed door for *Jean*? Had her being in that room catered to her wishes? Had she been given all that she needed in order to pass

peacefully? Who made these rules? Nobody told me, nobody asked questions. What if that meant that nobody had asked *Jean* what she had wanted?

A friend of mine said to me earlier this year; we all die someday, it's just a matter of when and how. It is the 'how' that I am interested in, and it is the 'how' that has lead me to conduct the following research.

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Chapter One: Introduction

Introduction

Limited literature provides insight into what takes place within an aged-residential care (ARC) facility during end-of-life (EoL), especially within New Zealand, even though approximately 40% of those aged >85 in New Zealand die in ARC facilities (Gibb, 2014). Much of the literature available focuses on the experiences of elderly facing EoL within their homes, hospitals or hospices in the UK, the United States or Canada (Goodridge, Bond, Cameron, & McKean, 2005). Therefore, a New Zealand based investigation into the experiences of EoL care in ARC facilities is fundamental to assist in understanding how death in ARC facilities equates with the expectations of the next-of-kin (NoK)/family member, and the elderly relative, through the NoK/family member's perspective. It is not a matter of questioning the services provided from the ARC facility, or critiquing them, but rather inquiring to see if the experiences obtained by the NoK/family member are reflective of their combined needs, wants and desires for this stage of life for their elderly relative.

This section introduces the definitions of the terminology used within this study, and the initial stages of the research, produced from brainstorming about what was needed to be identified through this research regarding EoL care in ARC facilities. The research goals and subsequent research question are presented, and then a brief summary is given which outlines the content in this thesis.

Terminology

Aged residential care (ARC) facility: A place where people who are elderly and/or unable to take care of themselves can live and be taken care of. The care provided by ARC facilities is classified into four levels; resthome care, long term hospital care, dementia care, and psycho-geriatric care. Some facilities provide all levels of care, some do not (Age Concern, 2015). In this study, the term 'ARC facility' is used to refer to all these levels of care.

End-of-life (EoL): This term is used to describe the time when death is approaching, and is mainly referred to as the last hours and days before death occurs. The judgment of approaching death can be made by either medical, social, or health care professionals, but the patient and their family are often the first to observe the approaching death (Ministry of Health, 2015; National Institute on Aging, 2015).

End-of-life (EoL) care: This term describes the response to the needs of the patient and their family during the EoL stage, when death is anticipated to be nearing. The response is in the form of supportive and palliative care, in acknowledgment of the families assessed needs, around the time of death as well as immediately afterwards. This term includes management of patient pain and other signs of illness of the patient, as well as the psychological, spiritual, social and practical support of the patient and the patient's family (Ministry of Health, 2015).

Palliative care: This term refers to the care provided to a person of any age with a life-limiting illness. A life-limiting illness is one that cannot be cured and will result in the death of the person, either weeks, months or years in the future. The care is provided at all stages of the life-limiting illness, by health care professionals such as General Practitioners and nurses.

Research goals and question

Two research goals were formulated to provide direction to this research, these were:

1. Explore how NoK/family members describe the EoL care their elderly relative received
2. In particular, explore the NoK/family member's experiences, perceptions and expectations around received EoL care for their elderly relative in the ARC facility

Therefore, the following research question was formulated:

What are the next-of-kin (NoK) and/or family member's perceptions of the end-of-life (EoL) care provided to their elderly relative who was a resident within an aged residential care (ARC) facility?

This area of research is difficult due to the delicateness of the topic; both friends, family members and the dying are undergoing an inevitable permanent transition that many

people do not choose to think about until closer to that time. The topic of death could be considered a taboo subject; an article from The Telegraph (13 May 2014) states that more than half of the couples in Britain are unaware of their spouse's end-of-life wishes. We generally don't want to talk about death with people whom we care about and are important to us. This creates challenges in capturing information which provides insight into the needs, wants and desires of those whose life is ending and of those they leave behind. But it also highlights the importance of an investigation such as this, as difficult as it may be. Talking about the experience of death and dying of an elderly person in an ARC facility means that we can understand the processes better, the surrounding issues within those processes, and ultimately help create an environment which supports all those involved.

Review of chapters

Chapter one introduces and lays the foundation for this research project.

Chapter two examines the literature on EoL care in ARC facilities, from both international and New Zealand based research. The literature review focuses on common topics such as: background information on current standards and measurements of EoL care and how these have created the EoL care currently present in ARC facilities. Studies which have also used the perspective of the NoK/family member and their findings, and studies which have investigated EoL

care using alternative perspectives, such as that of the registered nurse, doctor, health care assistant, and their findings.

Chapter three discusses the research methodology, which provides explanation behind the method and analysis used for this study. The research used a qualitative design consisting of semi-structured interviews. Thematic analysis was undertaken on the data collected.

Chapter four describes the procedures involved in obtaining ethics approval, recruiting the ARC facilities to support the research, and the recruitment of participants. It includes a description of the participants within this study and their relationship to their elderly relative.

Chapter five presents the results from the analysis using excerpts from the participants' conversations, and then discusses them in relation to the research question. Ten major themes were detected, along with ten sub-themes, and are presented in the same manner as told by the participants; a timeline from when their elderly relative's health declined, to the moments of the elderly relative's funeral.

Chapter six summarises the research project and the information in the previous chapters. It reviews the research question and provides a synthesis of the findings. It acknowledges the limitations of this research, and the aspirations for future related research.

Conclusion

This research looks to investigate the NoK/family members' perspectives on the EoL care provided to their elderly relative who was a resident within an ARC facility in the Manawatu region. The study aims to understand how the NoK/family members experienced the EoL care of their elderly relative, enabling insight into the processes and procedures that is EoL care within New Zealand-based ARC facilities. It gives insight into the challenges they experienced, their struggles, their needs, and their perception of what their elderly relative experienced during this time in the ARC facility.

Additionally, participants experience of the EoL care of their elderly relative will go on to affect their overall outlook of their relative's death, their memories; which connects to the way they are able to grieve (Lane & Philip, 2015). This insinuates that quality EoL care is not only important for the elderly relative, and how they die, but also for the NoK/family member. It brings awareness to wider factors and people involved when elderly pass away in an ARC facility.

Chapter Two: Literature Review

Introduction

This chapter addresses the current literature surrounding EoL care within ARC facilities for elderly. Investigations into previous research were conducted using databases; Psych Info, Discover, Scopus and Google Scholar. Searches focused on literature that shed light on current standards of EoL care and the practices used when elderly pass away in ARC facilities. Searches also focused on current and past research that used the perspective of the NoK/family member, as well as research that used alternative perspectives to investigate EoL care for elderly in ARC facilities. Searches were focused to these particular domains in order to better understand what has in the past and presently encompasses EoL care, and to obtain a wider understanding of experiences on EoL care for the elderly person within the ARC facility, from both the views of NoK/family members, and others such as health care professionals.

Current standards and measures of EoL care

The challenge that EoL care has, is to be flexible to be able to address individual needs, but provide a standard of care that fits a spectrum of needs that occur at some stage during EoL. A look into what standards and measures are used as a guideline to EoL care is fundamental to understanding how EoL care works, how it is applied, who by, and why. Mackintosh (2014) discusses the Liverpool Care Pathway, an integrated care pathway, that has been reviewed here due to its large influence on the EoL care in New Zealand and in the

United Kingdom to date. The Liverpool Care Pathway could be considered both a standard and measure of care, and is used when someone is thought to pass away within hours, or two to three days. It is holistic in that it assesses both the psychological, emotional and spiritual needs, as well as the medical. It provides a framework that centers on providing measures of comfort, the prescription of medications and the discontinuation of interventions for the dying person within settings such as Hospices, ARC facilities and hospitals (Gambles, Stirzaker, Jack, & Ellershaw, 2006). Although attacked for its lack of focus on communication and individual care (Marshall, Clark, Sheward, & Allan, 2011), Mackintosh (2014) suggests that this particular integrated care pathway has been, “shouldering the blame” for “poor practice in EoL care and decision making responsibilities” in recent years (p. 9), and that viewing the Liverpool Care Pathway as merely a tool – and not a treatment plan – provides a type of yardstick measure for the EoL care provided. However, others claim that the ‘tick box’ approach removes the ability for an individual EoL care plan that is backed up by “condition-specific and good practice guidance” (p. 9).

Additional to this, Watson, Hockley, and Dewar (2006) reviewed an adapted version of the Liverpool Care Pathway implemented within eight independent ARC facilities in the United Kingdom, as part of an action research project to install high quality care in ARC facilities. Using qualitative and quantitative research methods before, during and after the

implementation of the adapted version of the Liverpool Care Pathway, their research displayed six barriers to its implementation. These included the staffs lack of confidence and inability to understand the EoL symptoms, when to prescribe the appropriate medication, and having on hand the medication for the EoL resident in anticipation of their future symptoms. Even with the pathway in place to use as a ‘tool’, staff of the eight ARC facilities reported a low level of understanding of when it was appropriate to discontinue activities such as food and fluid intake. The study concluded that high staff turnover and lack of multidisciplinary team members working within the ARC facilities, was an uncontrollable barrier to the effective use of the adapted version of the Liverpool Care Pathway, and was partly responsible for these initial barriers.

Another standard of EoL care is referred to as ‘the good death’. A predominantly Western ideal where death is pain free, there is an open acknowledgement of the nearing of death, a death at home and surrounded by family and friends, an ‘aware’ death where personal conflicts and unfinished business are resolved, death as personal growth and death according to personal preferences that reflects the person’s individuality (Gott, Small, Barnes, Payne, and Seamark, 2008). The concept of the ‘good death’ is reviewed here as research has shown that the ideologies and frameworks we have around EoL care, are not always true or fixed within the elderly cohort and could be reflecting the social values of those who create them. Additionally, the ‘good death’

concept may provide expectations which are unrealistic with aging. For example, Gott et al. (2008) initiated a study in the United Kingdom with elderly people who had heart failure, to see what services responded to their specific EoL needs. The study consisted of home-based semi-structured interviews with 44 people with a mean age of 77 and focused on components of the 'good death'. The study found that several obstacles existed within the concept of the 'good death', firstly, researchers pointed out that patients experienced co-morbid conditions which alter the course of their illness, and suggested that an awareness of death may mean a loss of hope to the individual and potentially reduce the opportunity for personal growth. Interestingly, they stated that in an environment where palliative care practitioners are available, it is part of their role to help the dying elderly acknowledge their own authentic self in order to support personal growth. The above statement highlights two concerns for the 'good death' standard of EoL care within the context of an ARC facility. Firstly, the palliative care role is not always available within some ARC facilities, potentially meaning that many elderly people who pass away within this context may not be given this opportunity for personal growth. Secondly, if an awareness of dying is needed to acknowledge their authentic self, and for personal growth, then those who suffer from illnesses other than cancer, such as dementia, may not be able to engage in this process, which is a high majority of those within some ARC facilities.

The concept of the 'good death' was also explored in an

Australian study by Hart, Sainsbury, and Short (1998) and how the choices of dying people were either constrained or supported by this ideology. They noted how this ideology underlies the behaviour of caregivers and their goals of patients' care, and therefore creates a struggle to change dominant discourses around the prevailing 'good death' ideology, and allowing for other ways to die that center on that person's self and identity. They concluded from their study that there should be a reform of the 'good death' within institutions, including ARC facilities, in order to create a death that is unique and personal to the individual. Conclusively, it seems that the 'good death' concept is only available to those who age 'successfully' and 'healthily', is subject to context, and has little relevance for those who are frail, ill and the oldest old.

Within New Zealand, a large amount of work has been done on understanding and creating guidelines for EoL care that can cater to different patients needs within different EoL contexts such as the home, hospitals, hospices and ARC facilities. A recently released report by the Ministry of Health, *Te Ara Whakapiri: Principals and guidance for the last days of life* (2015), outlines provisions on providing the best possible EoL care for adults whose death is imminent. The report addresses medical, holistic and practical aspects of EoL care such as providing information to the patient and family on facilities and support services available depending on the environment where the patient experiences EoL. The report outlines best-practice principals and guidelines for a

range of stages within EoL including; a baseline assessment, ongoing assessment of the plan of care, and care after death. The report creates a plan of care that is broader, flexible, acknowledges the expansive time of EoL that is not just limited to when the patient is alive, and places importance on the patient's family, as much as the patient.

Additionally, a more local recent report from the MidCentral District Health Board (2015) which focuses on peoples' experience of palliative care, also acknowledges the central role of both the patient as well as their family and how much both parties are central to good EoL care. The report identifies themes that are holistic components of EoL care, such as the personalisation of care which encompasses ongoing conversation and information exchange between the patient and their family, how the personalisation of care may provide mitigating factors for the patient of wanting to be within another place of care, or not in care at all. It addresses the value of kindness and compassion towards the patient, sensitivity to context of the EoL care and its effects on the patient such as ensuring a welcoming, accommodating environment. Giving time which is not rushed, to both the patient and their family, was another theme that manifested, as well as acknowledgement of the resilience of the patient's family during bereavement.

These two reports display the milestones that EoL care has made within New Zealand, advancing forward from the Liverpool care pathway and ideologies of what death should

be. Both reports acknowledge areas that need further research and understanding regarding EoL care, such as the experiences of care within non-specialist environments. Particularly, the Midcentral District Health Board report suggests that more research is needed in order to obtain understanding of EoL care especially for elderly who reside within generalist and primary palliative care environments; environments which include palliative care within their normal standard of clinical practice, but are not part of a specialist palliative care team, within the Manawatu region.

The perspective of the NoK/family member

Research using the perspective of the NoK/family member gives further insight into how these measurements, standards and ideologies are received, perceived and understood by elderly and their family experiencing EoL care in an ARC facility. A quantitative study using an adapted version of the Memorial Symptom Assessment Scale Global Distress Index (MSAS-GDI), conducted in the United States by Hickman, Tilden, and Tolle (2001), addressed symptom distress of dying elderly through a retrospective report from their recently bereaved family members. Their research showed that stress was alleviated for the dying elderly through the presence of family and friends, and that the presence of family was potentially able to reduce the symptoms of the dying elderly due to better communication and familiarity, than the presence of health care professionals. Lynn et al. (1997) also conducted a study based in the United States from the perspective of surrogate decision makers to help

understand the actual experience of dying for the elderly. The majority of recruited participants were close family members (89%) of the elderly person who had died from non-malignant diseases as well as colon cancer or non-small-cell lung cancer. They focused on obtaining a reflective viewpoint, where they could revisit the last three days (72 hours) of the life of the elderly EoL person. The site of death varied with some dying in hospital, others in an ARC facility, and some in their own home. Scales were used to rate actions that had taken place over the three days and included variables such as perceived physical pain of the elderly person, emotional support received for both the elderly person and surrogate decision maker, as well as decision making and communication. They found that the majority of elderly people had passed away in a ARC facility rather than a hospital. It was noted that psychological symptoms were regularly addressed with pharmacological treatments; many of the elderly showed anxiety or mild to moderate dysphoria, which is viewed as common in the last three days of life. Pharmacological medications, in some cases very high doses, were also used in the treatment of pain relief with many surrogates stating that their elderly EoL relative requested care that focused on comfort, with some requesting more treatment and medication, even if the risk was experiencing potential distress.

A study by Goodridge et al. (2005) also investigated the last 72 hours of the elderly person's life in a Canadian ARC facility through the perspective of their bereaved family

members, registered nurses and health care assistants. Their study showed that emotional support for both the dying resident and their family, was key to good EoL care, as family members struggled psychologically watching their family member die and reported feelings of helplessness. Additional to this, Zerzan, Stearns, and Hanson (2000) reviewed the literature on the access of EoL care services in ARC facilities in the United States. They noted from the literature that surviving family members reported greater dissatisfaction with ARC facilities than any other component of terminal care, which may have been a product from the limited availability of hospice specialist services, reaching only 1% of those in ARC facilities in the United States, and few ARC facilities with staff who obtain EoL care expertise. Witkamp, van Zuylen, Borsboom, van der Rijt, and van der Heide (2015) used a questionnaire to investigate the quality of death for elderly people from the perspective of their bereaved family member, within a training hospital in the Netherlands. Their research showed that quality of death was related to the level of agitation and anxiety experienced by the elderly person, not being at peace with their imminent death, and appeared to be strongly affected by the support of health care professionals and staff attentiveness that the elderly persons' received. They also found that 52% of all elderly patients were reported to have discussed their preferences for medical treatment at the EoL, and that relatives' own participation in medical decision making, based on information given on patient disease status and treatment options, provided a positive EoL experience for

both relative and their elderly family member.

Additionally, a New Zealand based study by Bellamy, Gott, Waterworth, McLean, and Kerse (2014), conducting 28 telephone interviews with bereaved older adults recruited from the Brief Risk Identification Geriatric Health Tool trial, was carried out to investigate their views, experiences and sources of bereavement support following the death of their significant person. Their findings displayed how many of their participants had an anticipatory sense of grief, stating that their bereavement was “expected” and an “inevitable life event” (p. 98). These attitudes displayed how many of their participants found the use of bereavement support services as unnecessary, or were not considered during their time of grief, and were rarely obtained from social support services provided by hospice and government services. However, support was sourced and obtained from family, friends and social groups that the bereaved older adults were already involved in. What was also highlighted within this study was how the place of death of their significant person was reported to have dictated the type, level and availability of support the family member received. Participants whose significant person had passed away in a hospice were more likely to be offered some form of support services compared to participants whose elderly relative had passed away in an ARC facility or hospital.

Alternative perspectives on EoL care

The perspective of nurses, doctors and health care assistants,

is also beneficial in order to obtain a well-rounded perspective and understanding of EoL care within an ARC facility. A study from the United Kingdom by Ryan, Gardiner, Bellamy, Gott, and Ingleton (2011), focused on EoL care for elderly with dementia, and incorporated the views and opinions from participants from a range of different disciplinary backgrounds including nurses, doctors and allied health professionals. They conducted focus groups and individual interviews which showed that many nurses, doctors and allied health professionals try to understand who the elderly person was before their dementia set in, through the elderly person's relatives, in order to provide the assumed care that the elderly person would have wanted. This was referred to as the 'long view'. The researchers also noted how their participants placed emphasis on collective work ethic, such as working together in order to provide good EoL care. The participants suggested that barriers to providing good EoL care included power dynamics and egotistical hierarchies. An ethnographic study of death and dying was undertaken by Costello (2001) in elderly care wards in a British Hospital. Although the setting was a hospital, the study does explore the experience of elderly EoL patients from the perspective of nurses; many nurses who have worked in hospitals frequently move to, or have worked in an ARC facility at some stage during their career. The study consisted of 29 nurses, 74 patients and eight physicians using participant observation and semi-structured interviews. The three wards where nurses worked; acute assessment, continuing care, and rehabilitation, were assessed against

each other to build theoretical explanations for actions and thinking patterns of the nurses. Ultimately, the study suggested that nurses within these hospital ward environments, struggle with many forms of communication not just limited to that between elderly EoL patient and nurse, but also with the over-seeing doctors as well. Nurses were restrained from giving out information on the prognosis of the elderly patient and some even displayed a lack of ability to voluntarily engage with patients about death due to its sensitivity as a subject.

Cleary and Carbone (1997) reviewed the current literature on the barriers to EoL care by medical oncologists for elderly patients with cancer in the United States. It reviewed the struggle oncologists have with managing pain for elderly EoL patients, the barrier and impact when the elderly EoL person refuses to take opioids, and the psychological issues which occur around the time of death as a repercussion of medication and treatment. They stated that these barriers may be due to the current practices and beliefs of medical practitioners, the patients themselves and the health care system put in place to provide the care. Although their review focused on those with cancer only, they did in parts focus on elderly living in ARC facilities. Specific to this review, they noted that up to 80% of patients living in ARC facilities have reported pain and that many oncologists find this administration of pain management to the elderly during EoL care, daunting. The authors noted that education plays a fundamental part in the access of good EoL care, as 16% of

deaths in the United States occur in nursing homes. This supports the importance and reason to conduct research, inquiry and education into EoL care in ARC facilities within New Zealand, with our numbers being significantly higher; 40% of those aged 85 and above pass away within ARC facilities in New Zealand (Gibb, 2014).

A New Zealand based study conducted by Marshall et al. (2011), used the experiences, perceptions and views of EoL care from nurses, health care professionals and medical practitioners from ARC facilities within a District Health Board region. Likert scales and open ended questions were used. The findings from the open ended questions were slightly contradictory to the responses in the Likert scales. The Likert scales showed a confidence in caring for the EoL elderly residents, however the open ended questions exposed reduced confidence in caring for these residents. Difficulties which emerged included an insecurity in identifying when EoL care should begin and a sense of 'managing' EoL care in an environment where staff work predominantly in isolation and lack time. Staffing issues and timely response of general practitioners for medication prescriptions also added to the difficulties of providing a high standard of EoL care. The study demonstrated the participants' values regarding EoL care, and how this sometimes dictated their actions. For example, participants who viewed EoL residents as those who were at the end of a long life, instead of life ending due to disease, enjoyed working with the EoL residents. While participants who voiced that they preferred to avoid EoL

residents found the task of dealing with death and dying personally difficult to manage. Bellamy and Gott's (2013) New Zealand study also explored the views of healthcare professionals but from a range of settings including hospitals, hospices and ARC facilities, and focused on culturally appropriate EoL care. They conducted interviews and focus groups in order to initiate discussion on this topic with 80 participants in total. Their results showed a culturally sensitive form of EoL care, which was flexible to acknowledge the different processes for Maori, Chinese and Pacific Island families during EoL for their elderly family member. It highlighted the fact that there is great variance of what is considered 'good' EoL care between different cultures and ethnicities, and the tentative task of health care professionals obtaining and understanding these different values, norms and beliefs, all the while avoiding what is referred to a 'cook book' approach to EoL care for different cultural groups.

Additional to an awareness of culturally appropriate EoL care, is an awareness of the impact of the elderly person's previous environment, and how this impacts on their EoL care needs. For example, the transition from hospital setting to an ARC facility may determine patient needs, the demands towards the ARC facility, and the overall quality of EoL care the elderly experience. A New Zealand study by Connolly, Broad, Boyd, Kerse, and Gott (2014), used a census-like survey to investigate the relationship between mortality rates and the length of stay (short term stays versus long term

stays) of elderly living in ARC facilities. Their study surveyed 6,828 residents in total from 152 ARC facilities and showed that elderly are at a higher occurrence of mortality after initial admission into the ARC facility (80% survival rate after < 1 month). Those with high/complex needs and those who were referred from acute hospital wards made up most of this percentage of those who died within a month of admission to an ARC facility. From this, the researchers suggest that consideration needs to be given to appropriate place of care, the experience of transition to place of care for elderly and their family members, and the needs of people with limited life expectancy being placed within an ARC facility. The study also showed that non-specialist health care assistants felt inadequate knowing how and when to provide EoL care in an ARC facility and there is evidence that residents in ARC facilities receive average EoL care, inadequate symptom control and high rates of acute hospitalisation, but low rates of specialist referral for those who are dying.

Conclusion

Forty percent of older people in New Zealand die in ARC facilities, a further 10% die after moving back to public hospitals from ARC facilities (Connolly et al., 2014). The studies within this literature review have looked at the methodical practices and definitions of EoL care, as well as the views of the NoK/family member, health care professionals, nurses and other medical professionals regarding EoL care for elderly in ARC facilities. What is

presented here gives background knowledge to how EoL care is experienced, provided, assessed, addressed, what is needed regarding support, transition and pain management. We can begin to understand that EoL care education, support, collective teamwork from all health care professionals may be hugely beneficial in improving EoL care in ARC facilities. These studies also suggest that the understandings of EoL care vary amongst health care professionals, and how much health care professionals' views and values they hold about on EoL care, can greatly influence the type of care administered and received.

Additionally, this literature review that suggests EoL care is fluid and non-static, that its presence does and means different things to different people, within different countries. Armstrong (1987) addresses a type and kind of 'truth' regarding the dying which accurately sums up this chapter. He argues that truth in dying has changed and evolved over the years, it follows the waves and bends that is society through the centuries, sometimes being a public affair in the early 19th century, but has moved to the private, silent, quiet domain during the 21st century. This influences peoples wants and needs during EoL as well as the actions and behaviours enacted by health care professionals. By continuing investigations and research, such as this study, into the EoL care for elderly within ARC facilities, means that literature is kept up-to-date on the changes that each century brings for this phenomenon, and for those who are involved working with or for this context. Research such as this means that

knowledge and understanding on EoL care can keep in pace with advancing changes, the wants and needs of the elderly applicable to this situation and time.

Chapter Three: Research Methodology, Method and Analysis

Introduction

The methodology adopted for this research suggests that people's experiences construct their world and reality (Swartz, 2015). Qualitative research methods satisfy this methodology due to its ability to enable researchers to gather data on peoples' unique, complex, situational, personal experiences and behaviours, using either observational methods, interviews and other documentation (Rohleder & Lyons, 2015). The use of a qualitative design, using semi-structured interviews which took on an inductive approach, to research the NoK/family members experience of EoL care for their elderly relative while in an ARC facility, would not only satisfy the exploratory nature of this research, but also give voice to the NoK/family member as to how they constructed this particular phenomenon, and was therefore decided to be the appropriate method.

This chapter outlines the methodology which has guided the method used, and the type of analysis performed. It provides insight into the theoretical and methodological understandings of qualitative methods and its construction of qualitative research questions, interview questions, determining the number of participants required and the construction of the interview.

Research methodology and method: Qualitative inquiry

A belief of multiple realities, a commitment to identifying an

approach to in-depth understandings of the phenomena, and a commitment to the participants' viewpoints are some of the perspectives underlying qualitative inquiries (Vaismoradi, Turunen, & Bondas, 2013). Qualitative research is therefore extremely diverse, there is no firm set of rules, only principles or guidelines. The methodology behind qualitative research can be seen as its foundation, giving this form of social research guidance and therefore credibility (Treharne & Riggs, 2015). It assists the researcher in identifying the underlying reasons for the research and the formulation of the research question, aim, objectives and method (Braun & Clarke, 2006; Seale, 1999). The methodology adopted for this research did not aim to test anything, but to gain insight and understanding into a phenomenon. Therefore, the requirement to formulate a hypothesis, or pre-test a previously developed hypothesis, was not necessary. What was required was a research question that would reflect the methodology of the study; that peoples' experiences shape their realities, that there is no one 'truth' but understandings formulated from our lived experiences (Seale, 1999; Swartz, 2015).

Research question

Qualitative research questions can be broad, and literature suggests that without a firm underlying methodology, this can cause a lack of direction, clarity and focus when conducting the research (Bradley, Curry, & Devers, 2007). To articulate this study, and provide the clarity and focus it needed, an investigation into past and current literature was conducted in order to adopt a good understanding of the phenomenon and

concept, to identify a well specified target population and understanding of the context. Therefore, formulating a research question that was broad, but built from well understood terms and literature on EoL care. Due to the sensitive nature of the research topic, time available and ethical constraints, it was decided that the research question would enquire into the perspective of the bereaved NoK/family member in order to understand their experience of EoL care in ARC facilities. In particular, how they described the experience, their perceptions and expectations.

Interview questions

How the interview questions were asked, and their format, would dictate the extent to which participants shared with me their constructed experience of EoL care in the ARC facility for their elderly relative. Briggs's suggestions on methodologically rigorous qualitative interviews involves conducting fieldwork that aims to understand the culture of the anticipated participants, asking questions that can be easily understood by the participants, and therefore enabling quality within the conduction of an interview (as cited in Roulston, 2010). Kvale (1996) developed on this and produced a 'best practice' guideline some of which includes; the shorter the researcher's questions - the longer the participant's answers, the ability for the researcher to follow up and clarify on the participant's answer, and the interview which is a story; barely needing additional explanations and descriptions. As with the research question, the guiding methodology suggested that broad, semi-structured questions

would enable the sharing of the participant's story between the participant and myself, and allow the participant to talk freely about aspects of their elderly relative's EoL care in an ARC facility. Five broad interview questions (Appendix H) were put together which aimed to capture the participant's description of experiences, perceptions and expectations they had for themselves and their elderly relative regarding EoL care in the ARC facility.

The number of participants

The number of participants needed to investigate a phenomenon can depend on the depth and type of analysis used (Vaismoradi et al., 2013). The literature suggests that the 'ideal' number of participants depends on a number of factors when looking to conduct a qualitative study. Morse (2000), suggests that five factors should be considered in order to include the correct number of participants; the scope of the study - the broader it is, the more participants needed in order to satisfy the breadth of the topic under investigation. The topic under investigation and study design will also dictate the number of participants required - a clear and accessible topic might mean information is obtained easier, thus fewer participants may be needed. If the design is a longitudinal study, or conducted as group interviews, naturally more data will be obtained and fewer participants may be needed. Once underway, Morse (2000) suggests that the quality of data will determine if further interviews are required; if the recruited participants have not answered the question under investigation, more may be needed to obtain

further data. Lastly, he discusses the addition of “shadow data” (p. 4) experiences that the participant discloses that belong to another person’s experience, or comparing two different experiences to each other. This adds to the range of experiences obtained within a qualitative inquiry, and therefore fewer participants may be needed to satisfy the inquiry.

Additionally, if a researcher chooses to use thematic analysis to analyse its data, this can reflect the depth of the analysis conducted; a limited number of participants may be used to obtain a deeper understanding of personal experience, or a larger number of participants may enable a shallower form of analysis (Braun & Clark, 2014; Vaismoradi et al., 2013).

Within this study, the number of participants required to provide a sufficient amount of data to answer the research question was partially based on the type of analysis to be conducted, as well as the format and design of the study. Interviews would cater to either a single participant or a few at a time. The topic under investigation is moderately accessible, meaning that the occurrence of elderly dying in ARC facilities is common, however its sensitivity as a subject may dictate the number of NoK/family members who want to discuss the details of their elderly relative’s EoL care within the ARC facility. Therefore, thought had to be given to obtaining too much and “drowning in data” (Morse, 2000, p. 3). From this it was felt that around ten participants would be a suitable number to obtain in order to successfully reach data

saturation. Similar studies tended to use slightly more participants within their research (Goodridge et al., 2005; Hickman et al., 2001; Marshall et al., 2011), however to effectively complete this level of research; master's thesis level, anymore participants were felt to potentially overwhelm the restrictions of the study.

The interview

The interview was used as the method of data collection within this study. Its use was based on the methodological assumption of the interview as a tool that could effectively obtain an understanding of participants constructed experience of the EoL care their elderly relative received while in a ARC facility. Theoretical and methodological guidelines for conducting qualitative interviews are diverse and literature suggests that options will differ depending epistemology and ontological assumptions, and that there is more to it than simply asking questions and recording their answers (Rohleder & Lyons, 2015). Neo-positivist assumptions about qualitative interviews as a form of data collection are vast within the literature, what this assumes is that the participant has a 'inner self' which is not seen within everyday engagements. Semi-structured interviews are commonly used; questions are kept broad and open, and the researcher works carefully in a sensitive and attentive manner, contributes minimally and thus takes on a neutral role. The understanding behind this approach is that good questions, and reduced influence and bias by the researcher into the conversation, encourages 'honest' talk from the

participants and the ability for the participants 'inner-self' to be expressed (Roulston, 2010). Roulston (2010) suggests that 'romantic' conceptions of the interview process are created through the development of a sincere, trusting rapport between researcher and participant, where detailed understandings of the participant's experience in relation to the subject matter can be deeply understood. They seek to obtain both the interior; their 'inner self', and exterior; obvious displays of meaning and experience, of the participant through the interview method (Roulson, 2010). Alternatively, transformative concepts of the interview as a tool, seek to challenge the views of the participants, thus getting the participants to engage critically with their thoughts and aspects of their daily lives. It not only seeks to 'transform' how the participants view aspects of their daily lives, but also obtain data for research (Roulson, 2010).

In each case, qualitative interviews can be seen as a vehicle for the exchange of language, language which allows people to, "constitute our ideas and constructions of the world and reality" (Swartz, 2015, p. 46), in order to "inform understanding of the meaning that participants make of their lived experiences" (Roulston, 2010, p. 203). The methodology behind this research uses qualitative interviews to allow participants to share, express, and reflect on, deeper understandings of their experience that may not be routinely visible to the outside world. This form of access to the 'inner self' of the participant enables the uncovering of new ideas or understandings that may not have been anticipated at the start

of the research process (Britten, 1995).

Analysis: Thematic analysis

Thematic analysis is a method used within qualitative research for identifying re-occurring ideas and patterns within participants behaviour, actions and thoughts, which are relevant to the research question under investigation. It aims to allow an understanding of a phenomenon, using themes to relay common occurrences of the participants' experience (Vaismoradi et al., 2013). The method of thematic analysis adopted for this study was that of Braun and Clark (2006). They suggest that before anything else, specific criteria must be formulated to dictate what is to be coded or not, to reduce the risk of the analysis becoming overly subjective to the researcher's personal biases (Joffe, 2012). An element of subjectivity will naturally occur within research done by people (Vaismoradi et al., 2013), however criteria can help keep the researcher/s on track and focused on what to listen and look for when conducting qualitative interviews and reading the transcripts (Joffe, 2012). Within this study, the criteria reflected its founding methodology by emanating a broadness that focused on the experiences, expectations and perceptions of participants regarding their elderly relative's EoL care in a ARC facility. The dimensions of EoL care; emotional, physical, psychological, cultural and social, were included in order to help provide the criteria with focus.

Criteria was also formulated to acknowledge any wants, needs or desires mentioned by the participants to cater to any

unforeseeable topics relating to the EoL care of their elderly relative. The developed criteria revolved around, but was not limited too:

1. Their experience of the EoL care received by their relative
2. Their expectations of the EoL care received by their relative
3. Their perceptions of the EoL care received by their relative
4. Any reference to needs, wants or desires of them and their relative
5. Any reference to emotional, psychological, social, spiritual, cultural and physical dimensions of care by the participant and those perceived by their relative

After all interviews had been completed, the interviews were transcribed. This involved listening to each of the recorded interviews, while typing them into individual Word documents. It also included familiarisation with the data set. As part of thematic analysis, during and after transcribing, listening, reading and re-reading the transcriptions can assist with the identification of initial ideas and codes that become visible from the data set (Braun & Clarke, 2006). Noting down initial ideas and codes, after transcription and during familiarisation, was apart of this study's thematic analysis process.

Dedoose, a web based qualitative analysis site, was utilised to undertake the coding. Transcriptions and audio recordings of the interviews were uploaded into the database, and enabled a structured and organised generation of the initial codes. This can be done through the systematic analysis of all transcribed content and placing interesting content to a code. Similar ideas within the content are marked to existing codes or new ideas formulate the creation of their own code (Aronson, 1994; Braun & Clarke, 2006).

An important part of thematic analysis is the move from codes to themes, and how this process is done. Firstly, a theme is stated as a, “specific pattern of meaning found in the data” (Joffe, 2012, p. 209), or as something considered important in relation to the research question. The identification of themes helps to ‘shed some light’ on the research topic (Braun & Clarke, 2006; Vaismoradi et al., 2013). Consolidating the meaning of codes and placing them into relevant themes is the next step in Braun and Clarke’s (2006) method of thematic analysis, where all relevant data are gathered to format themes. Themes consist of both explicit and implicit patterns of content within the data, creating manifest and latent themes. Manifest themes can be direct, observable, or obvious references, while latent themes are subtler and/or implicit references within the transcripts. Manifest themes may draw out less obvious meanings within the data, thus creating and drawing attention to latent content (Joffe, 2012; Vaismoradi et al., 2013).

Naming a theme consists of reviewing and refining what the coded data within that theme relays to the audience, what it tells as part of the participants' stories, thus formulating a clear idea of what the theme is about and naming accordingly (Braun & Clarke, 2006; Vaismoradi et al., 2013). The naming of themes within this research was done using this method, and review and refinement were constant while generating the names of themes. What slowly began to appear throughout the reviewing of coded data and naming of themes, was a display of time-specific themes, unfolding a thematic timeline of events of EoL care that the participants experienced.

The number of times a theme reoccurs is sometimes important too, as this can show strength to how much a theme 'matters', however the occurrence of a theme may simply be its ability to capture a central idea within the data in relation to the research question (Braun & Clarke, 2006). The reoccurrence of the themes within this research was not restricted to a specific number, but the strength of particular reoccurring themes was noted. Mainly, themes manifested through the relatedness to the criteria and their ability to address the research question, this was intended to reinforce the study's focus on relaying experience, even if that experience belonged to only one of out the eleven participants.

Lastly, and as displayed within this study, Braun and Clarke's (2006) thematic analysis method includes the use of quotes

and paraphrasing with themes in order to help support and demonstrate the pattern of meaning within the data (Aronson, 1994). Quotes are used within the findings and discussion chapter of this study to provide support and reflect the meaning of the theme to the audience.

Chapter Four: Procedures

Consultation

The early formation of this study began with the IMPACT (Improving palliative care through research) group; a group of clinicians from Arohanui Hospice, other researchers from Massey University including psychologists, who had come together with a shared interest with EoL in different healthcare settings. More recently, they became interested in the happenings of EoL within ARC facilities for elderly people. My appointment as researcher for this investigation meant that consultation with the IMPACT group was central to making sure that the information we sought generated from shared aims and ideas about the topic. Dr Simon Allan and Dr Jean Clark shared with me their ideas on the topic; past research which had been conducted through the Arohanui Hospice and recommendations on conducting the research. My consultation with the palliative care educator for the hospice was central to obtaining background information on EoL care, which in most ARC facilities is referred to as either 'comfort cares' or a more common term, palliative care. An interesting insight from this was that there is no requirement that ARC facility staff receive palliative care training through hospice services, and the loose 'guidelines' available in New Zealand for providing palliative care. This led to my next discovery; there was no 'set' way to provide care to the dying in ARC facilities, therefore the use of the term 'EoL care', defined as the stage at which death is considered to be nearing, was used in this research to remove any confusion and focus on layperson understandings of palliative care

which may or may not exist within some ARC facilities.

The IMPACT group consultation included updates on my progress with the research, how I had decided to investigate the topic, ideas of recruiting participants, and the groups feedback to me on these topics. The following section outlines the procedure to obtain ethical approval, the recruitment of the ARC facilities, recruitment of participants, data collection as well as providing information on the participants' relationship to their elderly relative.

Ethical considerations

Ethical approval was obtained from the Massey University Human Ethics Committee; Southern A Application 15/38 (Appendix A). Organisational approval was sought from the three ARC facilities that verbally agreed to be involved in the research, this consisted of obtaining a letter of approval from each consenting ARC facility which was then passed onto the Ethics Committee. Key concerns for the ethic's application were; the recruitment of the three ARC facilities and participants as well as maintaining both ARC facility and participant anonymity, acknowledging the sensitivity of the topic, and actions to help mitigate and respond to a series of anticipated emotional responses from the participants.

Anonymity

Anonymity of the ARC facilities, participants' names and the names of their elderly relative was a central ethical consideration, in regards to exposure of names within the

research. Displaying names within the research runs the risk of potentially causing upset and friction between participants, their family members and/or the ARC facility, as well as reducing the honesty of the participants' experience within the interview. Pseudonyms were not used so all persons' names, places, and any other identifying information was removed from the transcription of the interviews. Interviews were numbered by their sequence of occurrence, and in cases where the interviews involved more than one participant, participants were referred to as either 'participant 1' or 'participant 2' within the numbered interview.

Sensitivity of the subject

Acknowledgement of the sensitive nature of the subject was an ethical consideration as it allowed me to become more prepared for any display of emotion by the participant during the interviews. Discussions between myself and my supervisors regarding how talking about this research topic with participants may affect them included:

- Talking about the kinds of EoL care their relative received may conjure up a mixture of unpleasant feelings or have these feelings surface once the interview is completed.
- The capacity the topic has to upset the NoK/family member, bringing about anxieties and fears the NoK/family member has around aspects of death or death itself, or strong memories with regards to losing their family member.
- It also had the potential to highlight negative aspects of the EoL care received, thus leaving the participant feeling

despondent or resentful and using the interview as a way to vent anger.

- Seeking the interview as a form of counsel, and as an opportunity to talk to someone about how they feel after losing their loved one.
- The resilience of the participants would need to be identified and addressed. Most people are resilient during bereavement due to support from family, friends and existing support groups/relationships within their community. However, some people may be less resilient due to poorer support networks, and therefore may experience a more complex bereavement.

To be prepared for, and therefore help support the participant with these potential feelings, I kept on hand the Health and Disability Commissioner (HDC) code of rights information pamphlet which details the participants' rights as a consumer of health services, as well as information on the correct procedure to lay complaints. Due to the relationship between myself and Arohanui Hospice, the Hospice advised that I was able to offer its bereavement, counselling and support services to the participants of the research if they seemed to be struggling, and/or experiencing extreme distress about the passing of their elderly relative, and advise that bereavement services available through Arohanui Hospice can be accessed directly or through the referral of their General Practitioner.

It was important for me to be prepared and to know what advice is appropriate in each situation. These were discussed and followed closely throughout the research between myself

and my supervisors. My contact details were offered to the participant at the end of each interview session in case the participant had any concerns or questions they needed to discuss.

Sensitivity to location and support

The interviews of the NoK/family member were arranged at a time and location suitable to them. Their comfort was of utmost importance due to the sensitive nature of the topic, so location was left up to the NoK/family member at a place where they felt the most comfortable while taking part in the interview. Options included their home residence or a privately booked library room on the Massey University campus. They were also offered the opportunity to bring the support of a friend/s and/or family member/s with them to the interview.

Recruitment of the ARC facilities

Initially three stage-3 ARC facilities; defined as a facility which provides hospital-level care, were approached by introductory phone call from a staff member from the Arohanui Hospice due to the pre-existing relationship these ARC facilities had with the Hospice. The details of the research were broadly explained by Arohanui Hospice before inquiring as to whether the ARC facility would like to discuss participation in the research further with the researcher. Details of the ARC facilities that wanted to discuss the research further, the name of the clinical manager and their contact details, were sent to me via email from the Hospice. I

then proceeded to phone the clinical manager of each ARC facility to organise a meeting to discuss their involvement in the research, the recruitment of participants, as well as providing them with an information sheet on the research (Appendix C). After the meetings, two of the three ARC facilities that I met with agreed to participate in the research. In order to help recruit the number of participants needed, an additional stage-3 ARC facility within the MidCentral DHB region (Appendix B) was approached some weeks afterwards using the same process, and this organisation agreed to participate in the research. Two of the three ARC facilities were located within an urban area while, the third was located in a smaller centre in the MidCentral DHB region.

The justification for selecting these ARC facilities was based on four factors; their pre-existing relationship with Arohanui Hospice, being a stage-3 ARC facility and having services that included hospital-level care, being within a one-hour driving radius to central Palmerston North, and the number of hospital beds available in the ARC facility. Too few hospital beds could reduce the opportunity to reach potential participants, while more hospital beds increased this opportunity as it was thought that a fair number of NoK/family members may not respond to the invitation to participate. Additionally, by limiting the ARC facilities to a one-hour driving radius, it reduced the chance of participants being located too far out of the Palmerston North/Manawatu region, which would cause technical issues for obtaining face-to-face interviews without having to use technology

such as Skype.

Recruitment of participants

NoK/family members who had recently experienced the passing of their relative while in an ARC facility, were recruited through the three ARC facilities that agreed to participate in the research. A list of appropriate potential participants was created on my behalf by the clinical manager, using the database of the ARC facility. The criteria for appropriate potential participants included;

- Their elderly relative had resided and passed away within either hospital or resthome-level care
- That they engaged or were involved to some degree in the EoL care of their elderly relative
- That they are able to speak fluent English; in order to reduce the need for translation and its associated costs
- Be located within a maximum one-hour radius from the center of Palmerston North (Appendix B)
- That their elderly relative had passed away between 2.5 and 5.5 months ago

This length of time after their elderly relative had passed away, is supported by other research such as Goodridge et al. (2005) who contacted family members two months after the death of the family's kin, first by letter then by telephone to arrange an interview. Hickman et al. (2001) contacted bereaved family members of deceased elderly people from ARC facilities between two and four months after they had

passed away, and Roza, Lee, Meier, and Goldstein (2015) also contacted bereaved family members and/or NoK after two months of the deceased passing away. This literature acknowledges that interviews with participants too close to bereavement can cause increased emotional upset and reduce the probability of participants wanting to participate in the research. Alternatively, interviewing participants whose elderly relative passed away longer than this timeframe may affect memory and recall of the events (Goodridge et al., 2005; Roza et al., 2015).

Once the list of potential participants was confirmed, I provided two letters to the clinical manager to send to each of the potential participants; a hardcopy letter from myself as the researcher, inviting the participant to partake in the study (Appendix D), as well as an electronic draft-template letter for the ARC facility, which they could change to their liking, also inviting the participant to partake in the research (Appendix E). An information sheet (Appendix F) which clearly outlined what the research was about and what would be required of the participant was also included. The letters were sent out by the ARC facilities in order to maintain the confidentiality of the potential participants, and the ARC facilities legal obligation to adhere to the Privacy Act 1993. I waited to hear from the potential participants after the letters were sent out instead of trying to contact the potential participants directly, as direct contact was considered both a breach of the Privacy Act 1993, as well as inappropriate by potentially causing the potential participants emotional upset.

Therefore, it was decided to leave it to potential participants as to whether they would like to contact me or not.

The potential participants who had received the letters in the mail and wanted to participate in the research, contacted me via either email and phone. Over phone and email I introduced myself and told them a bit about the background of the research. This gave them an opportunity to talk to me a little about their elderly relative and the ARC facility where they had passed away. After this conversation, I advised them what would be required if they were to participate, details of the interview, locations they could choose for the interview, and their option to have a support member present. I then asked if they would still like to be interviewed on the research topic, and if so, proceeded to confirm an interview date, time and location. Details of my initial conversation with each of the participants was noted down within a diary and placed under the order of the interview, such as 'Interview #1', 'Interview #2' and so on. Details included; the name of the participant who contacted me, the names of any other participants who would be present during the interview and their relationship to the contact person. It also included the contact person's relationship to the deceased elderly relative and the elderly relative's name, as well as details such as date, time, address and contact number.

Data collection

Data was collected using semi-structured interviews between myself and each of the participants using the five broad

interview questions (Appendix H). Each interview question included potential prompt questions for instances of silence, pause or to obtain further information after sentence conclusion.

Each of the interviews began with introductions upon arriving to each of the participants' homes, and thanking them for their time. As part of the start of each interview session, Seymour et al. (2002) recommends first providing background information about yourself as the researcher, which allows a gradual opening up of the topic under investigation and a familiarity to be created between researcher and participant. This technique was used within the context of this research, as a casual conversation took place shortly after my arrival and included conversations about myself, my background, and how I had become interested in EoL care and ageing. This allowed rapport to be established with the participant, and a small sense of familiarity created between us in order to help the NoK/family member feel relaxed and supported in sharing their experiences.

The conversation was then directed to explaining the participant's rights and role within the research; that all their personal details will stay private and confidential, and that names of persons will not be identified in the research, or the ARC facility where their elderly relative lived. Participants were advised that they were welcome to withdraw from the study at any time without having to offer an explanation up

until the time that the transcript was checked by the participant and returned back to me along with the transcript release authority (Appendix I), or if the transcript was not required to be checked after the interview, from this time onwards. The participant was advised that a recording device was to be used to record the interview, and any questions they had were addressed. Informed written consent was then obtained from each participant (Appendix G), and permission was asked to turn on the recording device before the interview commenced.

The interview began with question one; “Can you tell me a bit about (relative’s name)? How did they come to be in (name of ARC facility)?” This gave me background information on their relationship to their elderly relative, their illness and other details such as how long their elderly relative resided within the ARC facility. It also acted as a gradual progression into the research topic, easing the participant into the topic and removing any potential shock that direct questions could cause. During the interviews, each formatted interview question was asked when appropriate, and relevant prompt questions were used, or statements from the participants were revisited, to further enquire about a topic related to the aim of the study. A final question, “Is there anything else you would like to share with me in regards to your experience of (relative’s name) last few weeks/months?” was used to complete the study, as this signified that all interview questions had been addressed. The recording device was turned off and the interview was

announced complete once it was felt the interview had come to a natural conclusion. A \$20 MTA voucher was presented to each of the participants to thank them for their time and sharing their knowledge with me after the interview was complete. An explanation of what would happen with their data from the interview was given to each of the participants. I explained that I would type up the interview, which could be sent back to the participant for review, thus allowing them to modify the interview by adding and/or deleting sentences and comments, once it was typed up. However, none of the participants advised that they would like to see a copy of the transcript prior to analysis of the data. Interview times ranged from approximately 35 minutes to nearly two hours.

Participants

Eight interviews were conducted with 11 participants in total. Breakdown of the arrangement of participants can be seen below in Table 1.

Table 1. Breakdown of participant interviews by participant configuration and gender

Interview Sequence	Participant Configuration	Number of Female Participants	Number of Male Participants
One	Individual	1	
Two	Married couple	1	1
Three	Married couple	1	1
Four	Individual	1	
Five	Married couple	1	1
Six	Individual	1	

Seven	Individual		1
Eight	Individual	1	
TOTAL		7	4

Participants told me about their elderly relative’s age, occupation and ethnicity, as well as their relationship to their elderly relative, during each interview. A breakdown of this can be seen in Table 2.

Table 2. Participants’ background information and relationship to their elderly relative

Interview Sequence	Elderly Relative’s Details
One	Her elderly relative was a female in her 90s, who had diabetes, kidney failure, and heart failure. Her occupation was not disclosed. She was the mother to the female participant.
Two	Their elderly relative was a female in her late 80s, who had multiple conditions including a stroke and skin cancer, and had previously been a house and Navy wife. She was the cousin, but mother figure, of the female participant, and cousin-in-law of the male participant.
Three	Their elderly relative was a male in his late 80s, who had a heart attack and had previously been a farmer. He was the father of the male participant, and father-in-law to the female participant.
Four	Her elderly relative was a female over a 100 years of age, who had had bowel surgery, a stroke, a broken hip, and ultimately melanoma. Her occupation was a farmer’s wife. She was the mother to the female participant.
Five	Their elderly relative was a male in his late 80s,

	who had multiple conditions of lung cancer, post-war trauma, dementia, heart disease, bowel problems, diabetes and eventually pneumonia. He had previously been an engineer. He was the father to the female participant and father-in-law to the male participant.
Six	Her elderly relative was a male in his late 80s, who had a co-morbidities of dementia, lung cancer, post-war-trauma, diabetes, heart disease, bowel problems, and eventually pneumonia which was the cause of death. He had previously been an engineer, and was the husband to the female participant.
Seven	His elderly relative was a male in his early 90s who had reduced mobility caused by a systemic serious infection. He was a builder as an occupation, and was the father to the male participant.
Eight	Her elderly relative was a female in her late 80s who had serious complications during a hip operation, following that she had multiple strokes. Her occupation was not disclosed, but she was the mother to the female participant.

The information participants' shared in their interviews are a reflection of their own experience of their elderly relative's EoL care within an ARC facility. At times when they talked of other family members, their views were still understood as their own, and not the opinions of any other family members, or suggesting that they were speaking on behalf of their wider family.

All of the participants had either enduring power of attorney,

or considered themselves and acted as the lead decision maker and carer for their elderly relative. Reasons for this included; living within a closer proximity than other family members to their elderly relative, a closer relationship with their elderly relative compared to other family members, or degrees of a combination of the two. Only two participants had cared for their elderly relative within their own home prior to relocating to the ARC facility, however in all other cases the participants' elderly relatives had been independent and living in their own homes before relocating to the ARC facility. In all cases, the participants were highly involved in their elderly relative's lives not only during the time when the elderly relative was living in the ARC facility, but also prior to the move. This involved checking on their elderly relative consistently, spending time with them socially and running errands with them, cooking them meals and/or assisting with the cooking, cleaning and house chores of their elderly relatives' homes. In the cases where the elderly relative was living in the participant's home with the participant before moving to the ARC facility, the participant had taken on the provision of extended care including medication administration, tending to wounds, assisting with medical equipment, and daily activities such as showering and toileting.

Conclusion

The processes and procedures involved in carrying out this research included obtaining ethical approval in order to begin the research. This enabled consideration and

acknowledgment to the risks of this research, as well as how each of the identified risks; such as participants' reaction to talking about their deceased elderly relative, would be mitigated during the course of the study.

The recruitment of the ARC facilities, the initial contact of the participants through the use of the ARC facilities, as well as the interview process as the form of data collection, had to be well thought out, considerate to privacy, confidentiality and the sensitivity of the research subject, in order to carrying out research that was organised and focused to avoid causing upset, or offence to any of the ARC facilities and the potential participants.

Lastly, providing an overview of the number of interviews which took place, the configuration of the participants within those interviews, details of the participants' elderly relative and their relationship to their elderly relative, provides background understanding to the participants involved, and their elderly relative, without reducing the anonymity required for this type of study.

Chapter Five: Findings and Discussion

Introduction

The purpose of this study was to understand the NoK/family members' perspective on the EoL care provided to their elderly relative who resided in an ARC facility. The results will be re-presented in a way that highlights common themes, and will be portrayed using the same sequence of events as described by the participants during their interview. Quotes will be used from the participants' interviews to help support themes detected within the data. They will be presented in italics and using brackets where confidential details of the participants have been removed.

Setting the scene

The first theme that became evident was the occurrence of 'the crisis: the inability to look after themselves' where the elderly relative suffers an incident that causes the move to the ARC environment. This theme sets the scene and gives background information as to how the participants' elderly relative first entered the ARC facility and added to their overall experience of EoL care in an ARC facility.

The crisis: The inability to look after themselves

The participants began their story by first reflecting on the time when they began to see that their elderly relative was no longer able to look after themselves. They described a slow decline in their elderly relative's health, or in some cases, a slow decline which lead to a 'crisis point'. Some participants

noted the build up to the fact that their elderly relative's health was affecting their ability to look after themselves independently, and therefore it was no longer safe for them to be without full time care. While for other participants, the crisis point which was reached included the elderly person suffering a major health related incident, either in or outside of the hospital, and was the cause of their admittance into the ARC facility. Participants expressed their concern for their elderly relative, and used words such as 'unsafe' and 'dangerous', when describing the possibility of their elderly relative living on their own or with their spouse, especially after the major crisis:

The neighbours phoned and said she wasn't up, it was 'bout ten 'o'clock on a Saturday morning, half nine to ten, we went rushing around there with the front door key and found her in bed and I thought she was dead, um, rung all her alarms and phoned the ambulance and that, and I went with her [to the hospital] because I was down as next-of-kin on all the papers because I lived here, the others all lived a long way away (Int. 1, p. 2).

In the above excerpt, the participant describes the moment when 'the crisis' occurred for her and her elderly relative. She describes how protocols, which were put in place in order to 'keep an eye' on her elderly relative, since she lived independently and alone, were used as a signal that something was wrong, thus alerting her to quickly check on her elderly relative.

The ARC facility as a last resort

The participants demonstrated through the conversation, how after the occurrence of the crisis, they felt that the move to an ARC facility was the best, or sometimes the only, choice they had. In many cases, they felt that their elderly relative's health was too heavily affected for there to be any other choice and the move to the ARC facility was done almost immediately. Participants themselves described a realistic understanding, that although moving their elderly relative to an ARC facility came with a sense of guilt, it provided a better alternative than the risk of their elderly relative living on their own and being hurt, or living with them, where proper care would be difficult for them to administer due to other demands, or lack of medical knowledge and experience. This is where the ARC facility became the last resort, the last option for the participant who had responsibility for the elderly person's welfare:

I'd go round to do her evening meals and things, but it was just scary in the end to think that she was there on her own, and then she had a couple of falls.... And oh I was backwards and forwards too... all my, and I said to mum, 'look I think it's time we have a bit of look at resthomes'

Hayley: Yeah

I wanted it to be her decision, there was no way I was forcing my mum into care no matter what

Hayley: How did she feel when you mentioned it? What did she say?

Um, I, I just said um, I, 'this is dangerous, if you can't, boil your own jug and make a cup of tea, this is dangerous' and she agreed, and I said, 'do you think it's time now that we started looking at resthomes for the future', was my words, and she agreed (Int. 8, p.2).

Reluctance to the ARC facility

Almost all participants commented on the reluctance by their elderly relative to move into the ARC facility. Degrees of the elderly relatives' reluctance ranged from minor, such as putting off the idea or not wanting to view the ARC facility, to major, where their elderly relative displayed aggressive behaviour. In order to overcome this, participants described how they used a range of strategies in order to convince their elderly relative to agree to the move. Strategies ranged from gentle suggestions to which their elderly relative eventually gave into. Many participants told of how the ARC facility manager was used to help to encourage the elderly relative to move into the ARC facility, or health care professionals in the hospital to advise that this decision was one of a medical requirement. Extreme cases required the use of an ambulance to transport the elderly relative to the ARC facility because of the elderly relative's firm resistance:

So he went in there, completely against every bone in his body, so the only way we got him there, we did an ambulance

transfer, coz none of us would dare take him. (Int. 5, p. 3)

Additionally, participants spoke of the behaviour they viewed as resistance to the ARC facility environment by their elderly relative, even after the move to the ARC facility had taken place. Participants remembered comments from their elderly family member about always wanting to go home, not wanting things to change, not verbally stating their refusal of the ARC facility but giving emotional cues such as crying:

Hayley: Yes... and did she openly say that to you? That she didn't like being there?

No... not in so many words, but the way she acted and the things she said, I knew, yeah

Hayley: That she wasn't happy...?

A couple of times she'd cried, and you sorta.... 'I wanna go home...' (Int. 1, p. 19).

Participants commented on the reasons they thought that their elderly relative resisted the ARC facility environment. Many suggested that they thought it stemmed from the ARC facility being an unfamiliar and foreign environment, but even when the ARC facility environment became familiar and known, participants still described times when their elderly relative still showed reluctance; many participants placed this down to a loss of control and independence as the main factor for

their elderly family member not wanting to go, as well as be in, the ARC facility:

And she liked to be totally in control of everything, she never allowed anybody to do anything, when we went for dinner, we'd go down quite regularly to her place for dinner, and she wouldn't let you help, you'd literally picked her up and put her out the kitchen, one day I said, 'I'm doing the dishes'

Hayley: (Laughs)

But she's got to be in control

Hayley: Yeah

And that's why, she hated being there because she'd lost all control (Int. 1, p. 18-19).

In the excerpt above, the participant uses her past knowledge of the personality of her elderly relative to come to the conclusion as to why her elderly relative struggled so much with living within the ARC facility. She acknowledges how much of an effect the difference between the home and ARC facility environments must have had on her elderly relative due to her need to always be in control.

Discussion

Participants began their stories from the time that their elderly relative's health declined to a point that became

unsafe for them to live on their own. This point in their stories requires attention, as we can start to see the reasons of how and why elderly move into the ARC facility environment, that it was no longer safe for them to be within their own home, and why the move to the ARC facility was only considered at this very last point of threatened safety.

We can also start to gain perspective of their elderly relative's reluctance to leave their own home, even when they could no longer look after themselves. A qualitative study researching elderly living alone, and how they felt about their changing health and needs, highlighted that many elderly people display a passive sense of acceptance to their ageing, and stayed positive about what they can still do. Others fought to hold onto what activities they could still do on their own, and reiterated the frustration that came about by not being able to do activities that they had been doing their whole lives (Birkeland & Natvig, 2009). Therefore, it could be suggested that the move to the ARC facility was only considered after threatened safety caused by a health crisis and not before, due to the passive sense of coping 'ok' until their NoK/family member became too concerned for their welfare. These perspectives highlight the idea that the shift to the ARC facility environment is marked as a required social, safety and wellbeing 'point' in their elderly relative's lives.

Additional to this, having contextual knowledge as to what the elderly person's life was like prior to the move to the ARC facility means a deeper look into what the move to a

new foreign home and living arrangement could have symbolised for them, and therefore gives further insight into their reluctance to move to the ARC facility. For example, a New Zealand based study by Dupuis and Thorns (1996), suggests that buying, and living, in your own home, is synonymous with adulthood. Therefore, the requirement to leave one's own home could signify the removal of a type of adulthood and the meanings that are connected to that title; independence, decision making, control, and strength. This stage in the process also highlights the cultural value we place on the circumstances in which we live. Dupuis and Thorn (1996) go on to say that older adults identify their own home as a place of family, security and continuity. Thus the elderly relative's move from their own home, and leaving it for the ARC facility; a different context, may have removed some of those important factors for their elderly relative also. Using these insights, we can understand how the ARC facility becomes a place of 'last resort', and how it is a crisis that is ultimately the final point, and push, to leave their own home.

The new role

Participants commented on the different types of challenges they encountered while adapting to a higher degree of responsibility for their elderly relative. Their stories demonstrate different elements of a 'new role' which brought about personal challenges and demands; facing their elderly relatives 'crisis', having to organise the administration of the move to the ARC facility, what would happen to their elderly

relative's original home, organising having the assessment of their elderly relative by the hospital, and finding an ARC facility. Many participants spoke of taking up this role for the first time. They spoke of the challenges of constantly juggling the demands of seeing their elderly relative in the ARC facility with that of their current lives; home, family, work, the time pressures they felt, and navigating the correct medical decision to make for their elderly relative without knowing that their EoL care wishes were, having never been previously discussed. This was the establishment of the new role that the move to the ARC facility brought about for the participants:

And the registrar and the nurse were waiting for me at the door of her [hospital] room, she was in a room by herself, they said to me they can't wake her, she's in a very deep sleep and what did I want to happen. And I thought 'agh, mum what do you want me to do?' I thought cricky dicks, I don't, I know the last, the time before that when she was in hospital, she definitely wanted to be resuscitated. This time I wasn't quite so sure, I've got enduring power of attorney, I need to make a decision, what am I going to say, so in the finish I said to them as long as she's peaceful and as long as she's comfortable we'll just leave her (Int.4, p. 17).

The participants reference to 'leaving' her mother in the above excerpt, insinuates her decision not to intervene. In the hospital setting, intervening could mean administering different medications, or trying different techniques to wake

her mother, all which may provide different outcomes. The NoK role which determines her role to make these decisions, seems to be guided by acknowledging what she thinks her mother would want, as well as her own personal values. In this instance, her mother wakes and is then transferred to an ARC facility.

Demands on the participants also included having knowledge on things they previously knew nothing about. They told stories of how they had to manage the welfare and wellbeing of their elderly relative as best they could, many catering to demands of them wanting to come home or being unhappy, keeping them occupied, understanding their illness and managing its effects on their personality, and how best to keep their elderly relative comfortable:

I felt so relieved, cos my making those decisions on my own when I'm not a registered nurse, and don't have the knowledge of the medical system but have a little bit of understanding of it, it's really hard, it's like, I'm making decisions here on mum's life, should I making these decisions? My brother and sisters don't want to know about it, and I was alone, on all my decision making with mum so, and I was alone with dad so decided this time round it can't be that hard, I've been down that road, [laughs], you know, so um, I tried to make the best decisions to comf... to give her comfort (Int. 8, p. 6).

Here the participant questions her ability to make decisions on many aspects of somebody else's 'life'. Although care is provided by the ARC facility, it is still within the hands of the NoK/family member to be the decision maker for all aspects of their elderly relative's welfare. This excerpt displays the way that this participant viewed the decisions to be made - as part of a life, somebody whom they care very deeply for. Although all decisions around care, from any point of view, may not be done lightly, this describes a potential individual difference in decision making as a NoK/family member, as opposed to a health care professional, that comes with the added element of emotional obligation.

Drivers of responsibility

Participants expressed reasons for how and why they had become the designated NoK or main family member who was responsible for their elderly relative. The main driver of this was location, many of the participants were the only ones who lived close to their elderly relative and therefore became responsible for them more so than other family members who were located elsewhere. Additionally, participants spoke of how, as their elderly relative was family, it was part of their responsibility to fulfill this role. In some instances, it was expressed that their elderly relative had been a good husband/wife, mother/father and how this extended them to take up the role and stretch their responsibility further:

I did, cos I wanted too, anyway, because ah, you know, ah he he always worked very hard for us, I felt he deserved, that we

did the best we could, and as much as we could, so I felt that was, you know, that's what you do, isn't it? I mean, you know, he'd done his best for us? (Int. 6, p. 4)

The participant in the above excerpt discusses how, because she felt her husband had been good to her and their family, he deserved the very best that she could do, and provide, for him. She discusses her dedication to his care and needs as an expected, natural, obligation to her role as his wife, one that is considered to be 'what you do', just as she felt that her husband had carried out similar obligations, and 'worked very hard for us' throughout their lives together.

Discussion

What can sometimes be overlooked regarding EoL care for elderly in ARC facilities, is the demands this change places on their NoK and/or responsible family member. Stress and burnout by family members personally caring for elderly relatives is not uncommon in the literature (Brody, 1985; Clark & Rakowski, 1983; Greene & Monahan, 1989), and arises from a mixture of causes such as juggling multiple roles, the energy and time that is needed to fulfill those roles while also taking care of the normal day-to-day requirements of their own personal lives. Greene and Monahan (1989) state that this arises from the deep dedicated, obligation and affection that is felt by the NoK/family member towards their elderly relative. From the accounts of the participants, it seems that the same sense of stress, tiredness, and over-all juggle is experienced by these participants, even though the

'care' is maintained by the ARC facility. What participants explained to be the challenge was the ability to understand their new role, and to do this quickly. This required understanding medical terminology, what processes they had to go through and what services/contacts they had to make, as well as catering to the daily welfare of their elderly relative.

An unanticipated struggle that was voiced by some participants was the emotional burden from their elderly relative, either caused by the medication and/or illness, which is not commonly explored within the literature. They suggested that their close and familiar relationship with their elderly relative, caused them to be a type of 'unfiltered sounding board' for their elderly relative, meaning that the participants took on much of the 'emotional baggage' that their elderly relative was carrying for themselves. Therefore, the deep dedicated, obligation and affection (Greene & Monahan, 1989) that caused the participants to want to 'be there' for their elderly relative became a factor which caused demand and exhaustion, not solely due to making the time to go to visit their elderly relative, but to be exposed to their elderly relatives' personal and emotional difficulties. It displays how the experience of EoL care within an ARC facility for the NoK/family member can become not only demanding in terms of physical presence within the ARC facility, but also emotionally demanding and challenging over a long period of time.

Dealing with change in personality

Participants spoke of the change they saw in their elderly relative, comparing them to their 'old selves' which was before the onset of the illness or the before the crisis took place. The change in health caused personality changes such as anger, aggression, and reduced inhibitions. These were also amplified through the transition of moving into the ARC facility. In many cases participants spoke of how the changes in personality they saw were created by the ARC facility environment; frustration and fussiness from loss of control and independence, low mood and tearfulness from contextual changes, being out of their own personal home, and dealing with advanced changes in health and environment:

She grumbled and moaned more... towards the end where she never used to grumble before the stroke but she used to... 'don't like that, don't want that...' 'take that away...' [laughs] you know, 'oh for goodness sake, you miserable old bat', you know (Int. 2, p. 34).

Participants spoke of how these changes in their elderly relative's personality affected them during this time. Many spoke of the challenges it brought; to remain calm and not to react to the behaviour, and how the behaviour began to wear them down:

It's really like, having a.... child with a temper, like a tantrum, like having a child again?

Hayley: Mmm

That was, yeah even mum found that... that was yeah, your parents are kinda are like, he was like a child, but not, in lots of things

Hayley: Yeah, like a combination of the two...?

Yeah that was quite tricky, yes mmmm, but it was unrelenting, nothing was right, we weren't doing enough and oh, did us in (Int. 5, p. 34).

In the above excerpt, the participant expresses how the shift in her father's personality becomes difficult and a struggle to deal with. She identifies a role reversal between parent and child; her father and her swapping places, his child-like temper tantrums, as well as his 'unrelenting' demands, all which encompasses her referral to the both, 'child-like,' and 'adult-like' behaviour.

Seeing the moments of humour

Some participants reflected on times during the change in their elderly relative's behaviour and personality, that created moments that brought them humour and laughter despite the challenges that this change in personality created. They reflected on times where they 'just went along' or 'made light' of what their elderly relative was saying or doing, even if it didn't quite make sense or display their usual behaviour:

Yeah, and they were, and he said, 'They are... I had to go outside in the coal shed', and he said, 'And it was cold and there was no food, but I had to buy some beetroot and they weren't even cooked probably', [laughs], and mum laughed and he got really crabby when she laughed, he said, 'It wasn't funny you know!' [Laughs] (Int. 5, p. 16-17).

Many participants found moments that made them laugh even when their elderly relative was very sick, when their illness had changed their personality or when they had passed away. These are moments that the participants found ironic, or showed a side to their elderly relative's character which they had not seen before:

Um, the young guy went there and put his bucket in the room, he um, he probably wanted to go give her a wash and things, um, she just told him to, 'leave your bucket there and get out of there' [laughs] (Int. 1, p. 4).

Discussion

The participants' perspectives on their elderly relative's EoL care within the ARC facilities was partly about the difficulties in dealing with changes in their elderly relative's personality. Literature acknowledges that changes in personality do gradually occur throughout adulthood to varying degrees (Martin, Long, & Poon, 2000). These changes in personality were said to be not noticed, or only vaguely noticed, by the elderly relative themselves, which created a challenging situation for many participants who

reflected on the 'child-like' adult that their elderly relative had become. Behaviour such as this is well documented within age-related disorders such as Dementia, Alzheimer's Disease, Parkinson's Disease, and stroke patients, all which can bring about personality changes in those who are affected (Bózzola, Gorelick, & Freels, 1992; Rubin, Morris, & Berg, 1987). The participants' recounts of the humorous moments had between themselves and their elderly relative, may have been a display of the side effects of the elderly person's illness, such as dementia and stroke. Although participants were most likely aware of this, finding humor in these moments of inflated stories seemed to bring about a small sense of release and happiness for participants during a time that provided few occasions for laughter.

What is interesting to note was that participants never specifically spoke of whether they expected the personality change to occur, even after medical diagnosis. However, it was insinuated through the conversation with these participants, how unprepared they were for this change in behaviour, and having to learn to deal with it quickly and effectively. The challenge may have been for them, knowing who the elderly person was before their illness, and then having to adjust to this new and altered person.

Additionally, participants never directly spoke of how this change in personality affected their ability to discuss EoL decisions and care options with their elderly relative, but instead how the personality changes seemed to enhanced the

participants' role in making decisions on behalf of their elderly relative. Much of the literature discusses EoL care decision making as a collaborative effort between elderly person, their NoK/family member and health care practitioners, with little reference to the complications that occur when elderly patients' develop age-related diseases (Bekelman, Hutt, Masoudi, Kutner, & Rumsfeld, 2008; Clearly & Carbone, 1997; Connolly et al., 2014). Even research that investigates the barriers to EoL care for those with dementia, seldom addresses the difficulties and challenges for the NoK/family member whose elderly relative experiences changes in personality, and how this creates added demands on the NoK/family member with regards to making the best decision for their elderly relative's EoL care (Ryan et al., 2011).

The effort and kindness: Care within the ARC facility

When reflecting on the elderly relative's EoL care, the majority of participants could not fault the efforts of the ARC facility staff in their ability to provide care and support to not only their elderly relative, but to the participants also. In many cases, it was spoken how much the staff and management went above and beyond the participants' expectations of 'care' for the elderly relative. In the excerpt below, the participant states how much she appreciated the extra effort the ARC facility nurse went to, to get her mother out of the hospital and admitted into the ARC facility, where she felt her mother would be more comfortable. She shares how after her mothers return from hospital, the ARC facility

nurse arranged a room closer to the nurse's station, a new bed to provide better comfort and stronger pain medication, in order to cater to her mother's changed condition in health:

Because it was a weekend I think, they said it would take time for discharge papers or... she'd have to stay in the weekend but, [nurse] the charge nurse pulled out all the stops, she got all, she did everything and got her back that day, or that afternoon

Hayley: Wow

And then they changed her, within a week, they changed her room from where it was down closer to the nurse's station, with the proper bed, that was movable and softer, more comfortable and that for her, to look after her, and they got her on to the um, quite high doses of fentanyl patches and from that... that was in the September wasn't it? (Int. 2, p. 11).

When participants were asked what some highlighted moments were during the EoL care of their elderly relative, participants in many and most instances, commented about how much the staff had helped them by showing kindness and devotion to their elderly relative:

The highlights probably were the caring/kindness of the people in [ARC facility]

Hayley: Mmmm

They were there all the time, and also the kindness, the kindness, the added kindness, was the fact that she was hospital [level care] but she stayed in her room (Int. 4, p. 11).

The moments where the ARC facility staff showed effort and kindness towards their elderly relative brought a sense of ease to the participant, that their elderly relative was being well taken care of within the ARC facility. Additionally, it seemed to provide a form of support to the participants' role as NoK/responsible family member, by helping them manage the administrative and practical demands for their elderly relative.

The relationship built with the ARC facility

Participants spoke of the relationship that was developed with the ARC facility staff where their elderly relative lived. The relationship developed from many hours spent at the ARC facility which led to the ability for them to get to know staff and the surrounding premises. Many of the participants told how they felt they could talk easily and openly with the staff because they had had the opportunity to get to know them. In the same instance, participants spoke of how the staff talked more openly and freely to the participant about the care of their elderly relative, because of this developed relationship:

And the love, that they put in, and the care...

Hayley: Mmmmm

Oh it's amazing! I don't know how they do it!

Hayley: And so, um, what about an important part of the overall experience? What would be an important part for you?

That they would include you, and that they were always available, and that they were 100% supportive (Int. 6, p.13).

In the above excerpt, the participant expresses that an important part of her overall experience of the EoL care of her husband in an ARC facility was the support and care given towards her by the staff at the ARC facility.

Participants reflected on how they had preferred their relative to stay at the ARC facility during their last few days instead of being moved to a hospital or hospice, because of this relationship that was created between staff and elderly family member:

They they said... 'can she come back here [to the ARC facility] for palliative care?'

Hayley: Oh

[Staff said] 'We want her back here'

Hayley: Ooooh

Rather than having to go into a hospice or somewhere like that (Int. 2, p. 24).

This relationship extended to when the elderly relative passed away, in many cases participants reported how many staff showed great sympathy and sadness for their loss, and came along to the funeral. In the excerpt below, the participant describes her experience of the relationship she shared with the staff from the ARC facility. She describes what she took as a form of care towards her and her father, by the ARC facility, that went beyond medical care and routine, by showing their sadness for her loss, and by coming to his funeral:

Well, really good cos lots of them came to his funeral, and you know, there, yeah, and we've seen [nurse] in the supermarket and mum, and we've seen [ARC worker], you kinda of become like friends, but not...

Hayley: Yeah yeah you sort of got that shared experience

Yes, and they were really really upset, cos they did all like dad, he wasn't icky, you know, he was a nice, he didn't swear or, you know he was a nice man (Int. 5, p. 25).

Additionally, participants described the compassion, care and the relationship that continued after their elderly relative had

passed. In the excerpt below, the participant describes how much the staff at the ARC facility helped her 'settle' after the death of her elderly relative, and the developed relationship that still exists even though her elderly relative is no longer a resident within the ARC facility:

No they were amazing. Very, really amazing, they really helped settle, they helped me a lot. And they still do, they still give me a hug when I go and see [manager] and laugh and I love going in to see them (Int. 4, p. 7).

Alternatively, some participants also expressed times then they felt dissatisfaction with the care received at the ARC facility for their elderly relative. The dissatisfaction appeared to cause or potentially add to, the demand already felt by the participant. This, at times, created an added 'work load' for the participant through having to do many care jobs themselves or follow up complaints with management:

And that day I went to get her I walked into the rest home at one' o'clock to, and to organise, to have that time off, with all my jobs cos I do the childcare as well, was really hard, and to get the mobility taxi and I went in, and she was in one of her sleeping days and they put in a wheelchair and she's leaning like this [bends forward in her chair], and I thought, why didn't they ring and tell me?! I pre-organised all this?! And then [charge nurse] said, 'is your mum going out?' So 'yes... I have organised [the outing] for over the last week, how is this, these messages not get to you?' (Int. 8, p. 13).

What seemed to be the base of dissatisfaction for a small number of participants with the care received at times by the ARC facilities, was the lack of respect that was provided to their elderly relative. In the excerpt below, the participant describes how she experienced an ARC facility worker growl at her mother for not talking her medication. The participant expresses that the decision to have medication or not, was still within the rights of her mother:

I walked down the hallway and heard growling at her for not taking her medication, I said 'no, back off, she doesn't want her medication, don't make her have it', cos mum still had to, I thought mum still had to know that there was one person in this world she could trust that would be fighting in her corner and it was going to be me (Int. 8, p. 11).

The excerpt above displays the participant's dissatisfaction by the lack of respect shown towards her mother, and how the ARC facility worker used her position as an authoritative figure over her mother. The participant explains that because her mother couldn't tell the ARC facility staff to 'back off' herself, she felt that she needed to 'fight in her corner' and do this, to make sure her mother still had the same choices to make for herself as any other adult would.

Discussion

Spending long and large amounts of time in the ARC facility environment with their elderly relative, enabled an

opportunity for participants to create a relationship between themselves and the staff at the ARC facility. Relationships between parties build trust, they enable individuals to understand the characteristics of others and therefore form a relationship, which would be highly beneficial within an ARC facility environment where delicate subjects, such as medication, death and dying, are talked about commonly. A survey study by Marshall et al. (2011), using Likert scales and open ended questions to investigate the views and experiences of staff within an ARC facility, displayed the emotional investment some ARC facility staff make in order to develop relationships with residents and their families. Their participants viewed the development of relationships with residents and their families as part of the role and environment of the ARC facility. Many of the participants within their research shared views that this particular type of environment required ARC facility staff to go the extra mile and to make sure that both parties were well cared for. The theme 'the character of care' became evident within their research, which goes on to describe how the staff recognised the need for multi-dimensional relationships that required "special effort" (p. 692). The special effort made created close, emotionally invested relationships with the residents and their families, and care that was individualised to each resident and their family.

Additionally, the building of the relationship may also allow a more comfortable atmosphere for the NoK/family member to discuss personal desires for their elderly relative's care. A

newly created report by the Ministry of Health called *Te Ara Whakapiri: Principals and guidance for the last days of life* (2015) is a set of recommendations which aims to improve the quality of care for adults at the EoL. The report places the needs of the patient within the same category with those of the family, emphasising a multi-directional relationship between health care professionals and both parties. One of the provisions of the report states the importance of allowing the needs, wants, thoughts and wishes of both the patient and their family to be voiced, thus encouraging good communication and listening skills, and assisting in building a relationship between all three parties. Although not all needs of the family may be able to be met, it is the listening and hearing of the NoK/family member's concerns, thoughts, wants and needs, which can help the NoK/family member through the experience of losing their relative. Thus these actions can establish grounds for a relationship to develop, as well as creating a comfortable and encouraging atmosphere for the NoK/family member to voice their needs.

Additionally, a qualitative study which investigated the relationship between nurses and intensive care patients, states that the development and maintenance of the relationship between the nurse and the patient's family, is just as important due to the ability it has to affect patient outcomes. They go on to suggest that when a relationship between the nurse and the patient's family is established, and maintained, families feel more supported, patients' received more relevant care to their needs, and nursing staff are able to individualise

patient care (Hupcey, 1998).

What is shared: Participants talk with their elderly relative

Participants talked about the types of conversation they had with their elderly relative during their time in the ARC facility. Many participants and their elderly family members shared memories about the past together, the war, their family and people they used to know:

Got her, talking what she could remember of the past

Hayley: Mmm

She used to go back in time, easily, and she liked to share that life, she was in the army in Britain during the war, and she liked to share that time and she the, ah she had a lot of friends... yeah (Int. 2, p. 6).

Participants mentioned times when the elderly relative only wanted to talk about themselves; about what was wrong with them, their ailments:

But mmm cos dad was quite difficult cos he was so negative, like it's quite hard to talk, to people everyday, what do you talk about?

Hayley: Mmmm

You know he only wants to talk about himself

Hayley: So he didn't want to talk about, as you said he...?

No he only talked about himself and what was wrong with him (Int. 5, p. 11).

Keeping their elderly relative updated on family circumstances was mentioned by many participants, and helped to initiate conversation between the participant and their elderly relative. This prompted in many cases, stimulating conversation by the elderly relative where their thoughts and opinions were voiced, and created improved communication between them:

No she got my name out... most of the time and sometimes I'd be really concerned about a family member and I'd go in and I'd gossip to her about the family member and 'what do you think I should do mum?!' And she'd get quite a few words out then! It's like gawh!

Hayley: [Laughs]

[Laughs] She'd sit up in her chair! She'd give me some good advice, like wow, that was good [laughs] (Int. 8, p. 7).

In some instances, participants reflected on the inflated and elaborate stories their elderly relative talked about. In most cases the participants mentioned how they found these

conversations far from the truth, but none-the-less entertaining, and therefore followed through with the conversation:

But he used to come out with some great yarns, and he won the, he won three million in tax, but then it went to a racehorse, and he was sure he won, dad was always onto it, you know, but I s'pose it's just part of getting old, but he used to come and tell you some good stories, [laughs], you know, he used to crack-up about these stories, 'really dad? oh yeah' [laughs] (Int. 7, p. 2)

Wanting to go

A difficult conversation that participants appeared to struggle with was when their elderly relative began to talk of wanting to die. Talks of wanting to go home escalated into talks of wanting to die, placing a large amount of grief and guilt on the participants. In the excerpt below, the participants reflect on times when their elderly relative showed her distress and commented on how she wanted to die, and how the participants dealt with hearing those comments:

[Participant 1] A couple of times she'd cried, and you sorta.... 'I wanna go home'

Hayley: Mmmmm

[Participant 1] This was like after being there...

[Participant 2] A couple of times, being in the ARC facility, she said 'I just wanna die...'

Hayley: Yeah

[Participant 2] She said that a few times

Hayley: Yeah

Hayley: And had she been in the rest home long, or...?

[Participant 2] Oh over a period of 5 years, two or three times, she said that

Hayley: Yeah

[Participant 2] I dunno what it was, a low moment or...

[Participant 1] Yeah, all I could do was hug her, and say 'I know love, I know....' (Int. 2, p. 19).

During this part of the interview, participant one displays her distress when remembering hearing her elderly relative wanting to die. Her voice becomes sad while speaking the last few words, she looks down into her lap and her eyes begin to water. This memory of her elderly relative wanting to die seems especially painful. As noted earlier, literature suggests that death as a subject is taboo because it is difficult to do between people who share emotional bonds due to the

distressing thought of losing someone they care about (Walter, 1991). This excerpt expresses not so much the taboo, but the pain, sadness and loss that the participant feels when the topic of wanting to die is brought up.

The funeral versus the EOL care

Some participants spoke of the conversations had between themselves and their elderly relative regarding funeral arrangements, but never was it mentioned that there had been a discussion on what type of EoL care their elderly relative had wanted; EoL care was voiced as a matter of funeral arrangements. In some cases, the elderly relative had taken care of the funeral arrangements themselves and merely advised the participant that it had been sorted:

Dad was quite organised, he had his funeral all organised, you know you had to fill out the forms for how you wanted it and all that stuff so we did that, that was quite useful, in fact when my brother and sister and sister in law were here we went and chose a coffin and all that (Int. 3, p. 1).

Others mentioned how their elderly relative had brought up a conversation to discuss what type of funeral they would like:

Um yeah it was, mum wasn't going to have, she said to me one day when I went to see her, I think this was before she had her hip done, I mean before she had her leg done, she said now, I walked, she was sitting outside in the sun, 'now about my funeral', and I thought 'oh here we go', I'll just sit

down, no 'how are you' sort of thing, [laughs], 'I don't want any nosey parkers', I said 'ok that's fine, oh we'll just have private funeral', I said that to myself, thinking right that's fine. She repeated this several times and I thought oh well let's change the subject, so the next day she said something to me again and I said to her, 'mum you've got quite an extended family', 'Oh I want all the family there', and I thought oh, you want, you want everybody there, so you won't be having a private funeral (Int. 4, p. 18).

Again, we see within another context how the topic of death comes into play, or doesn't. Unlike the previous sub-theme which addresses occurrences of death being talked about directly, within this sub-theme, the participants' elderly relative has completed or addressed the funeral as taking care of their EoL arrangements. It may not be a conscious avoidance of talking about death, on the part of the elderly relative, but more a socially constructed way of thinking about EoL which is fixated around the funeral (Walter, 1991).

Discussion

Participants shared their experience of the conversations had between themselves and their elderly relative, during the moments spent together within the ARC facility. What seemed to come through as important was the *act* of conversation, whether its aim was to keep their elderly relative talking, and therefore functioning, a task that many participants said was difficult due to the largely reduced daily activity of the elderly relative, or as a vehicle for “trouble-

telling” (Grainger, Atkinson, & Coupland, 1990, p. 198).

Participants spoke of topics that ‘ignited’ their elderly relative into conversation, such as talks of the past, family on-goings, inflated stories that brought humour, while others shared how communication was used as a vehicle for distress. The occurrence of conversation with the elderly is commonly overlooked as part of the care plan within ARC facilities, Grainger et al. (1990) suggests that talk with the elderly is more than just an accompaniment to any plan of care, but should be part of the, “communication, health and ageing rubric” (p. 192), as it adds to the elderly relative’s experience of care within the ARC facility, and in some cases their wellbeing and identity as a recipient of care.

They go on to discuss the typologies of talk between both the family member and their elderly relative, and how this influences what is discussed within the context of an ARC facility environment. Parent-child relationships and their communication styles are said to fit somewhere within five categories; pluralistic; based on open communication and sharing of one’s own opinion, protective; based on filtered conversation in order to protect one another, the environment-sensitive family; who shares information gained from inside and outside the immediate environment with the rest of the family, the interpersonal-distance sensitive family; is the opposite, it seeks to conceal information, as leaking information gained from inside or outside the environment would be considered a flaw in ones character. And lastly, the achievement-sensitive family; where tasks are completed

with confidence and slight competition between other family members (Grainger et al., 1990). Grainger et al. (1990) suggests that the type of communication; how much is shared, and what is shared between family members, will depend on their communication style. This may give some insight into the lack of conversation between participant and their elderly relative regarding their wishes if a health 'crisis' occurred or when their health needs become more dependent, therefore leaving the NoK/family member to make many of the decisions on their own about their elderly relative's EoL care needs.

Additionally, family communication styles combined with avoidance of talking about death due to the difficulties of the conversation, may have contributed further to the lack of discussion around EoL care wishes between elderly relative and NoK/family member. Walter (1991) examines the societal influences, history and approaches to the avoidance of talking about death, and suggests that a taboo about death did exist among the white middle class, but this taboo is slowly reducing and becoming more expressive. He suggests that another societal approach is that death isn't forbidden, but hidden from our view within our everyday society, and therefore prompts little thought of plans for our own death until we are faced with it amongst our own social circles. Aspects of these two approaches may have created the "unease and embarrassment" (Walter, 1991, p. 15), that comes with discussing dying and death between parties who are emotionally connected to one another, and may give

understanding to its lack of acknowledgement between the NoK/family member and their elderly relative.

Multi-dimensional influence of pain

Concerns about pain seemed to be one the most prominent themes which had a multi-dimensional influence on the participants' experience of the EoL care of their elderly relative within an ARC facility. The participants reflected on how much they struggled with watching their elderly relative go through the experience of acute and/or chronic pain and suffering, and how much it caused the participants their own personal emotional pain:

You could see him going downhill and downhill and downhill and downhill, and he wasn't anything more, having his, and used to yell out with the pain before hospice came

Hayley: Hmmm

And then I think they put a morphine, um, I think it was... you know, like a cap in there, for his pain relief, and um yeah, so it was a bit, sad, you know with his suffering, suffering, you never like seeing anyone suffer, and that was probably the worst part of it, you know, um, yeah but um... (Int. 7, p. 7).

The participant above reflects on his memories of his father experiencing pain and how much his father suffered because of it. The recognition of his fathers increased pain has a follow on effect causing pain and suffering to the participant.

Thus suggesting that the pain felt by the elderly relative is not just limited to them, but seems to have an emotional element and influence onto their NoK/family member.

The experience of pain also encompassed an emotional element for the elderly relative, and was not only limited only to the experience of physical pain. Participants described their elderly relatives struggling to accept their new living environment; the ARC facility as 'home', their talk of not wanting to die, or leave their families. In the excerpt below, the participant describes how her husband did not want to leave her, referring to his death, and the pain he felt from this. She describes how she had accepted death as a fact of life, but how he was struggling to do the same:

A week before he died, he was crying and I said 'what you crying for?' he said, 'ah, I'm upset' he said, I said, 'why are you upset for?' he said, 'I don't want to leave you'

Hayley: Hmmmmm

I, I said, 'I feel sorry for you', he said, I said, 'you don't have to feel sorry for me', I said, 'I'm alright', I said, 'I've accepted it', I said, 'don't do that now', I said, 'I... I accept what comes, comes', I said, 'and and it's not in the way', I said, you know, I said, 'what will be will be and that's it', I said, 'I've got no regrets about anything', I said, 'we've done what we could', I said, 'you've done enough, you've done plenty'

Hayley: What did he say to that?

I said, 'you can't anymore', 'yes' he said, but he didn't want to end it, he didn't want an end, but I said, 'I'm afraid it will come one day', so I did, I could say that to him, yes I could, I could say that to him, and ah, but he didn't ah, no kept it to himself but I mean, once you go you go, and I, I was really prepared for it, I accepted it and I'm at peace with it (Int. 6, p. 11).

Participants described how the medications their elderly relatives took to reduce their pain and provide comfort, had also helped reduce the emotional pain the participants experienced caused by seeing their elderly relative suffering, and gave them a sense of comfort also. In the excerpt below, the participant talks of the difficulties she experienced watching her mother suffering during her slow decline in health, she talks of how the medication became the best option for both her, and her elderly mother, and how it provided them both comfort:

Um, best for my mother, you know, pain-free, everything, not just lying there, I've seen people just lie there for years, they don't get any better. It hurts, it hurt me more my mum just lying there and um, not processing or not getting any better, you know, that would hurt me more than what it's... we are still grieving but not we are not seeing my mother suffering you know? (Int. 1, p. 8).

Additional to the administration of medications, participants reiterated that they used other methods in order to help alleviate and reduce the emotional and physical pain that their elderly relative was in. These included keeping them entertained and distracted by taking them out as much as they could, sitting with their elderly relative and talking with them:

Hayley: And so most of the time you spent with her, 'sorta just being there?

Yeah I'd get a cup of tea or cup of coffee, and go and sit with her yap away and I'd put a TV in her room and the TV would go, and she'd have rock n roll music she loved, so I'd put that on for her as well

Hayley: Oh good

She had some Christian music I'd didn't really like, but I d put it on occasionally [laughs]

Hayley: [Laughs]

... [laughs], try and put the news on and the weather, cos she loved the news and the weather

Hayley: Oh nice

You know, and at the end I was taking yoghurts in and cold drinks, and lemonades and things that she enjoyed (Int. 8, p. 7).

The health care personnel as expert

At times when participants felt it was important to have their elderly relative as pain-free as possible, the ARC facility nurse became the expert in the administration of medication to ‘manage’ the occurrence of pain experienced by their elderly relative. Participants spoke of how they communicated to the nurse their wish to have their elderly relative to be comfortable as possible, thus giving the expertise over to the ARC facility nurse on how to proceed next:

But yeah, and even his morphine, they didn’t want to give him too much, I said no that’s fine, but he does have to be comfortable, you gotta make sure that he’s ok

Hayley: Mmmm

And I said, ‘you know, you’re the medical people but from what we can see’, I said ‘you know, I think he, probably could do with something’ (Int. 5, p. 21).

Participants spoke of moments where they referred to the ARC facility nurse as more knowledgeable than themselves regarding medication and EoL care practices. The participants acknowledged and attended to the fact that

medications were needed for their elderly relative during this time, but that their medical understandings of them were limited, which allowed them to be comfortable with placing this responsibility in the hands of the nurses, and therefore making the medically based decisions:

Yes, yeah yeah. Medically, they need, the RN's are there, the doctors there so she can do. They know best what they are doing, I don't have that kind of knowledge (Int. 1, pg. 6).

In other instances, participants were aware of the medicine doses and how they affected their elderly relative. Many participants explained occasions where they had to weigh up the positives and negatives of the medication that was given to their elderly relative, mainly with regards to how it affected their elderly relative's personality, demeanor and their suffering. In some cases, participants voiced how they felt that medications interfered and simply extended the life of their elderly relative beyond what was considered 'natural'. The participant in the excerpt below suggests that while she wanted her mother comfortable, and not to suffer, she felt that in some ways giving 'too much comfort', and therefore medication, was extending her mother's life and causing her mother prolonged suffering:

We interfere too much, we try to... as human beings we try to give them too much comfort by giving them that at the end, and I think that's so wrong, I think, this is all part of life, we designed to die, our bodies will shut down and it won't be

nice probably at most of the time (Int. 8, p. 6).

Discussion

Pain was a central theme within the interviews as it encompassed many different areas; how the physical pain of the elderly relative inflicted emotional pain upon their NoK/family member, as well as the emotional pain experienced by the elderly relative. The occurrence of pain included how the physical and emotional pain of their elderly relative was dealt with, including medication; where the ARC facility nurse became the 'expert', as well as alternative distractions to pain by the NoK/family member such as conversations, and just 'being there'.

Pain is widely explored within the literature on EoL care. In most cases, the literature investigates and discusses how physical pain is managed, by whom, when, and the decision makers involved. However, within this study, the experience of pain for both the participants and their elderly relative was not limited to a physical dimension. The emotional influence from the occurrence of pain in an EoL care context is not as advanced within the literature, and encompasses discussions on the psychological repercussions of approaching death, and how elderly EoL patients and their families, manage this emotionally. For example, an older study by Lieberman (1965) uses the observations of the family member to describe the psychological processes of the elderly person as they begin the process of death, with family members acknowledging their elderly relative slowly withdrawing

themselves away from others in a suggested attempt to protect themselves from the anxiety of separation from their family. His study also suggested that the emotional pain the elderly EoL person experiences may be a reflection of their ability to cope, or not cope, due to disorganised thoughts as a repercussion from age-related illness and/or age-related personality changes.

Additionally, what is interesting is that within the literature, management of emotional distress and pain of the elderly relative is discussed within the context of the NoK/family member's home with the NoK/family member being the sole carer to their elderly relative, or within the ARC facility from the staff perspective (Horrell & Stephens, 2011; Ryan & Scullion, 2000). But the participants' recollections of their elderly relative's EoL care within this study, suggest that their responsibility did not stop because the ARC facility environment existed, and that nurses are available. In fact, the participants' reflections suggest that providing emotional support and, sometimes by just 'being there', reduced not only their elderly relative's distress, but the distress that the participant experience by seeing them in emotional and physical pain. A study by Ryan and Scullion (2000) found that participants felt guilt, grief and selfishness after placing their elderly relative in a ARC facility, therefore the family member's deep, dedicated, emotional obligation to their elderly relative to provide their own form of 'care', may function as a relief to their own pain in that they had fulfilled their 'duty' as the NoK/family member (Greene & Monahan,

1989).

Lastly, the participants' references to the administration of medications to their elderly relative by the nurses, reflects one of the distinctions between family caregiving and professional caregiving. Much of the literature on pain medication revolves around the trained professional, and how they 'manage' the symptoms effectively with the use of medication. From the views of the trained health care professional, pain management during EoL is about finding the right 'balance' in order to provide comfort to the elderly person, thus reflecting them as the trained expert (Clearly & Carbone, 1997; Costello, 2001). A study by Costello (2001), interviewing nurses from elderly care wards displayed how the nurses viewed their role as mainly the administration of medication to help with the suffering, patient distress, physical and psychological pain, as well as keeping the elderly person pain-free and therefore, comfortable. But what some of the literature also highlights are the difficulties that health care professionals have in administering pain relief to elderly, and finding the right balance (Clearly & Carbone, 1997). Thus, although some of the participants looked towards the nurses for knowledge on pain and medication management and medication, on many occasions pain-relief and symptom control could be best approached from a united team, where the nurse and NoK/family member work together to counter-act both physical and psychological pain from the processes involved in EoL.

Letting go: Anticipatory grief

The process of letting go of their elderly relative was discussed throughout the majority of interviews with the participants. Letting go encompassed seeing the beginnings of death, and preparing for the event of death of their elderly relative while they resided within the ARC facility.

Participants spoke of how watching their elderly relative deteriorate in health, made them come to terms with letting them go into death. The participant below discusses how her and her husband began grieving for their elderly relative from the time she moved to the ARC facility, and how this move prompted her to accept that her mother's death was near:

Um, well it was different for me being, seeing everything. It did hurt me, still hurts me, but it was best for her. She wasn't well, wasn't going to get any better. You know, and, so we just accept, she's not suffering you know, she's not just lying there just... It would be hurting us more if she was just lying there and suffering, it was a very quick process for her at the end, which um... makes us grieve us better that way (Int. 1, p. 2-3).

This process of letting go was self-noted; participants told of how they did not need to be told by health care professionals at the ARC facility that death was very close, and were able to notice the signals of death themselves; an increase in pain, struggling to breath or merely function, changes in breathing, coherence, energy, food and water intake:

There was a couple of them [staff] that were really exceptional in what they did and they informed you what was going on, and I think you got to see, to tell that dad was you know, going to go shortly, I picked it anyway, I could tell, you know

Hayley: Mmmm

And cos you have your own thoughts about you know, you know, he's not looking good, you know, and some days you go in there and he'd be as white as a ghost, you know, and you thought 'oh that's not good' (Int. 7, p. 14).

In the excerpt above, the participant describes how he could see that his dad was 'going to go shortly'. He uses comparisons between the regular visits to his father within the ARC facility to gauge his father's health, and notes changes in appearance as indicators to the declining health of his father.

Anticipation of their elderly relatives' death also influenced how they felt about the news of their death. Participants noted how, although they were extremely saddened by their elderly relatives' death, it was not unexpected:

It was still a shock but it was, it was an expected shock really wasn't it, I mean, we knew she was going down hill... (Int. 2, p. 27).

Letting go was also talked about as a process that still existed some time after their elderly relative had passed away. Through the participants' grief they were in the process of letting them go, understanding that they were no longer around, that there was no need to go to the ARC facility anymore was also a common theme:

[Participant 1] I never... I knew it would be hard... because of the way I felt about her... but I didn't realise it would be as hard... yeah I thought because she's not my real mum and because of this you know, sure I'd be upset and all the rest, I didn't realise um, how, just how tough it would affect me and for how long, found it really hard... when we went to this cemetery the other week, I carried the box [of her ashes] up... and I said to [cousin] I'll carry it, [laughs], we got out the car, cos it's the way you walk up to the top of the RSA thing in [location], but I made sure that [cousin] who's the, who was the daughter, got on her knees and put her in, cos that's, that was her job, but I found that hard, putting her in the ground that was like my saying goodbye all the time she was here it wasn't too bad, this sounds stupid aye? [laughs]

Hayley: Still felt like she was here?

[Participant 1] Yeah... yeah... yep

[Participant 2] And I mean, the afterwards the gap in your routine as well you know, from going up there three and four times a week...

[Participant 1] You feel lost, you don't know what to do with yourself (Int. 2, p. 38).

Alternatively, for other participants letting go was about obtaining a sense of peace, both for themselves and a sense of peace for their elderly relative:

I was soooooo relieved, I thought at least you're at peace now

Hayley: Mmm

I could accept that quite easy, and I really haven't cried much about it. Ah ah I feel; I've got nothing to cry for... (Int. 6, p. 6).

The participant in the excerpt above states how the peace she felt after letting go of her husband, came from her feelings towards him not having to suffer anymore and having had a fulfilled and long life.

Existing until death

Some participants talked of when they considered their elderly relative's life to have ended even before they had passed away. Life, in their opinion, had ended for their elderly relative, and they were simply existing until they passed:

Which for us, the end was really quick, like it was only, he was only in bed a day, um but the end-of-life for us has been over about 18 months (Int. 5, p. 1).

Many participants specifically commented on their elderly relative's quality-of-life. Some talked about how the medication had made their elderly relative drowsy and increased the amount of time their elderly relative spent sleeping, how many could only sit there all day due to reduction in physical abilities, and how reduction in health had caused them to wear medical equipment that had reduced their ability to be mobile, thus affecting social aspects of their life:

Yeah, so all he could was look out the window really, which is really sad, because he was an avid reader, he collected clocks, he fixed clocks and he was an engineer so he had that kind of brain, you know, fixed things and get machinery going but um, it was a shame that he couldn't have that as a hobby to keep, you know, himself active (Int. 5, p. 19).

Many participants commented about how they thought medication and high levels of care were part of the reason for this extension of life, when life had really stopped occurring for their elderly relative:

[Participant 1] All those things, and but my sister and I particularly, he'd outlived his time and they keep people alive now with medication, they have too, but it's too long

Hayley: Mmmmm

[Participant 1] You know, it's and they feed them so well, and look after them so well and that's great, but I think back in the day, that you and I would have been dead...

[Participant 2] Earlier

[Participant 1] Yeah earlier, and really are we doing them any favours? I don't know

Hayley: Yeah

[Participant 1] Dad would say yes because he didn't want to die

Hayley: Mmm

[Participant 1] But really, what quality-of-life did he have? (Int. 5, p. 13).

The importance displayed in the above excerpt is the difference of opinion regarding quality-of-life. As opposed to her late father's opinion, she explains how she feels that medications were doing no 'favours' by extending life that has no quality, but admits that her father might have felt differently; that he did obtain quality-of-life from the medications.

Discussion

The participants' stories reflected on how they regarded their elderly relative's EoL as not just the last few days before death occurred, but the time from when the 'crisis' occurred and their elderly relative became a resident within the ARC facility. This prompted the process for them to begin to 'let go'. It suggests that grief didn't just start from the time of death, but from the time when their elderly relative's health became critical, in combination with the acknowledgement of very old age. In a study by Goodridge et al. (2005), the nurses they interviewed acknowledged the extended time of grief for the family members. They spoke of how family members watched their elderly relative "slowly going downhill" (p. 230), and how the family member knew their elderly relative was dying and waiting for that moment of death, the angst this caused the family members, and the display of grief they showed from the moment of illness and decline for their elderly relative. Additionally, an older study reviewed the literature on anticipatory grief, and its ability to function as an emotional "safeguard" for bereaved relatives against the death of friends and family (Fulton & Gottesman, 1980, p. 45). Their review showed no significant mitigating effects on the depressive symptoms involved in grief between participants who had lost a relative after a long terminal illness, as opposed those who had lost a relative to a short illness, and suggested that anticipatory grief merely extended the time that the bereaved family member was shown to be within a 'state of grief' and loss.

The conversation of letting go, moved onto the participants' opinions regarding the administration of medication and how it unnecessarily kept their elderly relative alive, when they considered that their life had already ended. Participants' expressed how important it was for them to keep their elderly relative comfortable and pain free, but many participants felt that through the extensive administration of medications, and the high level of care received, that their elderly relative's life was extended well beyond what it naturally should have been. A study which looked at the perspective of doctors treating elderly patients noted the doctors' dedication to keeping the elderly person alive. The author suggested that this was due to the medical model and teaching practices of medical professionals, where it is ingrained in them to act on all possible solutions to keep the elderly person alive (Wilmot, Legg, & Barrett, 2002). Alternatively, another study had contradictory findings with participants' expressing their dissatisfaction with medical professionals for not doing enough to keep their elderly relative alive, thus expressing their desire to sustain their elderly relative's life for as long as possible (Lindhardt, Nyberg, & Hallberg, 2008).

The extension of life through medication was connected to the participants' feelings towards quality-of-life for their elderly relative, and the continuation of their suffering. A study by Farquhar (1995) which interviewed elderly people from ages 65 and over, showed that quality-of-life is something that is connected not just to health, but how health impacts on the elderly person's ability to socially engage in

aspects of life such as relationships, activities and hobbies. Many of the elderly participants' reports of satisfaction and dissatisfaction with their quality-of-life were due to a combination of both age, how their age was affecting their health, and their inability to engage in social aspects of their life, such as relationships with others and their ability to still engage socially. Therefore, quality-of-life for elderly people with ARC facilities may fluctuate depending on their own personal values, and extent of fulfillment in their social and physical abilities. Additional to this, family members own opinions of what they deem as 'quality-of-life' also depends on their own personal values. Quality-of-life for elderly relatives was investigated using the perspective of the family member by Stewart, Teno, Patrick, and Lynn (1999). Their study suggested that how the family member viewed their elderly relative's quality-of-life, was determined by the family member's personal values and meaning attached to their own lives.

Conclusively, this theme suggests that opinions on quality-of-life, medications' role in the extension of life, and the goal of reduced suffering within EoL care is fluid and open to interpretation of both the NoK/family member as well as the elderly relative themselves. This reinforces the idea that EoL care should be tailored too, and discussed with both the NoK/family member and the elderly relative in order to achieve the best, and most relevant EoL care outcomes for each party.

The good death

Participants expressed opinions of what they had wanted for their elderly relative during their EoL in the ARC facility, and therefore suggested what they considered to be ideally a 'good death'. Comments on what they considered a good death revolved around; how they wanted their elderly relative to pass away, how much their elderly relative had come to terms with their own mortality, who was there when they passed; that their elderly relative was not alone, what medications would be given and how much, and how much pain they experienced:

I think she was just didn't feel well and the drugs were just making her... phew, yeah, but that that was ok, I was fine with that, the one thing I didn't want, I didn't want a hard death, I didn't want her... wasting away in bed, I didn't want her just, disappearing because she couldn't eat, I didn't want her tube feed in anyway, I didn't want her crying and being scared, I didn't want her wrapped with pain (Int. 2, p. 15).

Participants spoke of these ideals they had, in comparison to the actual event of their elderly relative passing in the ARC facility. Many suggested how things had not gone to their ideal plan of a good death. In the excerpt below, the participant retells how she viewed the death of her father-in-law as 'horrible' as it did not fulfill, or reside, with her ideals of how the build up to death should occur:

It was a horrible time, whereas Dad's death was lovely.

[father-in-law's death] was miserable for everybody because he didn't always recognise the kids, he sometimes thought you were somebody different (Int. 3, p. 5).

It's the way we die

Participants used of the events that lead up too, and the event of, their elderly relative passing away, to suggest that they were concerned over the lack of control they had over the way they would die. Participants recollections over the lack of control suggested that they were wary of their unknown death, with many participants advising that if they had known the way their elderly relative was going to die, and how they were going to die, death would be less scary:

I'm scared of dying, it's the way I die (Int. 2, p. 15).

Participants conversations and anticipations about the way they would die made them reflect on how societies take care of their elderly. Some participants compared how the elderly are cared for in other countries, or how they are cared for now, as opposed to 60 years ago in New Zealand:

Because my grandparents, when I was in the 1960s they lived with us on and off, cos there was no ARC facility, so got that to measure against as well and all I can remember as a child at the age of nine, granddad going into hospital and a fortnight later he got pneumonia and died, and grandma did the same, two weeks they were in there, got pneumonia and died, I do remember them having some pills but not many so you know, they they would have had just as many health

issues as what these people are having, was just done differently, um, and the families cared for them, well now the families 'have opted out to care for them', and we use excuses like their too busy and they've got jobs, well we've just become a greedy society, we want all the best now, so that's how it is, but um, going back, the 1960s was the right way for people to die, they lived with their families and if they didn't live on their own, and they hardly had any medication (Int. 8, p. 13).

Conversation moved to participants sharing the ways in which they would want to pass away, after having experienced the death of their elderly relative. Many used the experience to understand what they did and didn't want for themselves:

And I hope that I've got my faculties enough, 'Beg your pardon? Are you looking after me?' Or, 'Beg your pardon are you talking to me!' [laughs] (Int. 8, p. 19).

Discussion

In this study, participants shared thoughts on how they wanted their elderly relative to pass away, their ideals for this phenomenon and stage of life, and how much their experience and memories of the EoL care of their elderly relative in an ARC facility, shaped their views. This was how they shared their perceptions on what they thought to be a 'good death', a term which is not uncommon in the literature when exploring family and elderly needs regarding EoL care

(Ellershaw & Ward, 2003; Seale, 2004; Steinhauser et al., 2000). The participants' opinions on what they wanted for their elderly relative enabled an understanding on what they valued during EoL. They shared how they didn't want their elderly relative to suffer, and be in pain. In a study by Steinhauser et al. (2000), pain and symptom management were also a central feature of a good death. They noted that their participants feared for their elderly relative dying in pain, and but also wished for their elderly relative to come to terms with their own death in order for them to feel a sense of completion with their lives.

Some participants additionally stated how they wished for their elderly relative not to be alone with they passed. In the study by Goodridge et al. (2005), their participants shared their concerns and ideals with the nursing staff, as to how they didn't want their elderly relative to be alone when they were passing away. Additionally, a study by Seale (2004) using media accounts, suggested that the thought of dying alone is commonly seen as 'bad' by many individuals within society, and that many people feared this happening to those they cared for as well as themselves. Being by their elderly relative's side when they passed away may have been important to the participants in their concept of a 'good death', in a bid to alleviate some of their anxieties about the 'loneliness' of death.

Additionally, participants' reflections on societal processes now compared to 60 years ago regarding caring for family,

suggest their idealism for holding onto, and keeping family relationships close, by caring for their elderly relative themselves in their own home, as opposed to an ARC facility where the relationship may become lost.

Participants values on their ideals of the 'good death' will influence how 'good' or 'bad' they perceived their elderly relative's EoL and death to be. It also provides insight and a reflection of, what the participants wanted for themselves when their time comes to die after experiencing the EoL of their elderly relative; a 'good death', which is quick, not prolonged by medication, in their own home, and with family around.

The influence of family

Participants talked of how the interactions with their immediate and wider families affected their overall capabilities of caring and being responsible for their elderly relative. Many talked of times when their families provided a great sense of support and cohesion in coping with the strains that this time brought, such as visiting their elderly relative together, and having family meetings to discuss their elderly relative's health and welfare within the ARC facility.

Participants talked of times when they provided support, or when support came in the form of other family members helping to meet the needs of their elderly relative by visiting them at the ARC facility. It also included other family members making tough decisions when the participants couldn't, and standing up to their elderly relative when they

became difficult. In the excerpt below, the participant explains how she stood up to her elderly father while he was in the ARC facility, after she found out that he had been giving her mother 'a hard time' about taking care of him and bringing him back to their home:

And then we'd say, 'look we're not talking about it anymore but you know that, that we're not,' and then he'd get really crabby, but you can't re-hash it everyday (Int. 5, p. 16).

Other participants praised their family for providing support and 'just being there' for them. In the excerpt below, the participant explains how much her husband's support meant to her when he came along to the ARC facility with her, after getting a phone call in the early hours of the morning saying that her mother had passed away:

Yes [husband] came with me, I didn't think he would, and I was quite prepared for him not too, I had steeled myself for the fact that I would be on my own

Hayley: Mmmm...

But he came with me, he was amazing, he was, , but he was an amazing man, he was really supportive, it was great to have him sitting there (Int. 4, p. 21).

However, others described times when they needed the support of their families although they felt they failed to

receive this. Reflecting on these times brought up emotions of resentment, anger and disappointment by some participants, towards those in the family circle who they felt had failed to provide the help or support that they needed during this time:

My bother and sisters don't want to know about it, and I was alone, on all my decision making with mum so and I was alone with dad (Int. 8, p. 6).

It seemed that the memory of having support, or not having support, from the participants' family still had an effect on them, either positive or negative, even after time had passed since their elderly relatives had passed away. The participants all spoke of support vividly, and as something that they needed in order for their own emotional and social wellbeing in order to cope with the demands that came with being responsible for their elderly relative.

Discussion

Support towards the NOK/family member in times of high stress and demand seems to be essential to enable coping, emotional wellbeing and providing a good sense of care towards the elderly relative. However, in most cases, participants advised of times when this support was less than available. Ross, Mirowsky, and Goldstein (1990) suggest that the structure of the family unit can either hinder, or help the individuals within it. A good supportive, family structure can help cushion its members against threatening events, and

therefore spread the load of demands amongst its members, while a family structure that lacks support and understanding can increase the required demands and compromise its members' health. Zarit and Zarit (1982) also go on to suggest that severity of burden for those caring for elderly extends from factors including the caregivers pre-existing coping capabilities and the social support available for the caregiver.

This supports findings within a report by the Midcentral District Health Board (2015), on people's experiences of palliative care. The report acknowledged how a person's own established social support network; such as friends, family and organisations they are involved in, will determine the resilience of the NoK/family member during bereavement. Complexities a bereaved person may feel with regards to their loss, can arise from poor social support networks, and may require the intervention of social services within the community to help provide support during the time of bereavement. Those whose social support network is vast, and have the support of family, friends and club/groups within their community are more likely to show resilience during the time of bereavement and feel reduced desire to seek out community social services (Midcentral District Health Board, 2015).

From the conversations with participants, it was evident that in both cases of good and bad support, the majority of support that was wanted by the participants was that from the family. Shanas (1979) states that emotional support has

become something is now provided by the state through institutions and by civil servants, since family bureaucracy has reduced the ability for inter-family support in some situations. However, she states that even still, the desire for family support stems from what she calls “intimacy at a distance” (p. 170), where the desire to be emotionally close, but still maintain some physical distance from each other, originates from the bonds that are formed within the makings of the family unit. This could help understand how the experience of family participation was a central experience and focus for the participants, how it became a fundamental part to the participants’ overall experience of their elderly relatives’ EoL care, even when support was obtained from the ARC facility.

Grief and the funeral

Participants spoke of their struggle to manage their grief alongside organising the funeral for their elderly relative so soon after their death. Many participants described this time as challenging due to the emotional and administrative demand, with some participants explaining that they had to go through this process and manage it, on their own. In the excerpt below, the participant reflects on a time when she had to continue making the required decisions on behalf of her mother, immediately after her mother had passed away in the ARC facility:

And then all of sudden the undertaker is there wanting to know what you want for your mother’s funeral and you’ve

got to think on your feet so that's all part of planning and preparation and managing (Int. 4, p. 17).

In some situations, during times of loss and mourning, the people left behind take time out from work and commitments in order to reflect on the life of the deceased (Walter, 1999). The participants in this study reflected on how much the processes that occurred after their elderly relative passed away, had taken a toll on them, how they felt the desire to take time out, but were required to adjust quickly to the loss of their elderly relative, and then organise a large gathering within days. In the excerpt below, the participant talks of the difficulty she felt having to organise all funeral arrangements immediately after her mother had passed away, as well as being the contact point for people and decisions, when she was still dealing with the grief of losing her mother:

Not in, not when I'm grieving, not when I just want to be left alone, and you know, just don't want to be around people at all (Int. 8, p. 17).

Being the sole point of contact for all arrangements, the participant describes how overwhelmed she felt having to make a large amount of decisions quickly, as well as deal with many people at one time. She describes how, in her grief, all she wanted was to be alone.

Discussion

Participants stories enabled an understanding that although

their elderly relative had passed away, the demands of being the NoK/family member to the elderly relative still continued. Many told of the one last ‘push’ in order to respond to the fast pace of organising the funeral, the decisions that needed to be made, and to make those preparations before being able to grieve for their loss. A study by Harding et al. (2012) investigating the demands on caregivers providing at-home palliative care for cancer patients, advised of similar demands that the funeral arrangements made on them. They reiterated that this stage was an important part of their role as main caregiver of the dying person, but admitted the challenges of this stage, such as juggling the organisation and “managing practicalities” (p. 1977), while handling their grief. Other literature acknowledges the importance of having funeral arrangements pre-organised in a bid to reduce stress for the NoK/family member (Harding et al., 2012; Steinhauer et al., 2001). Additionally, the report by the Ministry of Health, Te Ara Whakapiri: Principals and guidance for the last days of life (2015), suggests that as part of the provision of care, a conversation should be had with both the patient and their family on their values and beliefs, which may assist with their after-death care, needs, and funeral arrangements. Thus suggesting that if ARC facilities work with these principals and guidelines, they would play a part in assisting and supporting the family with funeral arrangements and could potentially reduce some of the experienced grief and strain as re-told by the participants within this study.

The above literature highlights why the theme of grief and

the funeral arrangements became such a central idea from the participants' stories, as their memories partly focus on times of demand, struggle and stress. However, literature fails to focus or consider the grief for the NoK/family member, while following through with the demand of the funeral arrangements, whose elderly relative resided within other contexts such as an ARC facility. It may be the assumption that when receiving serviced care within a ARC facility for elderly relatives, the demands of NoK/family members are reduced. Or that after the elderly relative has passed away the role of ARC facility is complete. However, if anything, the participants' stories within this study demonstrate the extended emotional demand that this stage of the EoL care process caused for them, and therefore highlights the importance of attention and support to be given this stage.

Chapter conclusion

This research found ten themes and ten sub-themes from the data collected, which support the research question under investigation. These themes display a timeline of events that the participants all shared, and displayed how their experience of their elderly relatives' EoL care within an ARC facility consisted of a multitude of stages.

The themes found within the data suggest that EoL care within an ARC facility encompasses a large amount of emotional and physical demand, exertion, and management from the NoK/family member. Although at times, the relationship with the staff at the ARC facility acted as a

mitigating factor, the participants still express the types of strains the event of EoL care of their elderly relative caused for them, even though the ARC facilities provided serviced care for their elderly relative. This demonstrates the how the role, and potentially the perspectives, of the health care professional and the NoK/ family member may differ. Both provide support and degrees of care, but the NoK/family member's experience is emotionally laden; their struggles revolve around the obligation and dedication they feel towards their elderly relative, how this influences their decision making, their actions towards their elderly relative, and their elderly relative's actions towards them.

Chapter Six: Summary

Introduction

This thesis aimed to investigate the NoK/family members' perceptions of the EoL care that was provided to their elderly relative within the context of an ARC facility. Its main purpose for sharing the participants' stories was to create an understanding of the events that surround EoL care within an ARC facility from the vantage point of the NoK/family member. Additionally, to also provide an insight into the emotional, psychological, social, spiritual, cultural and physical dimensions that encompass EoL care in an ARC facility, and to develop an awareness of what the participants experienced, their expectations, their needs, wants and desires for themselves and their relative. This chapter reviews the research question, synthesises its findings, and compares it with other New Zealand research on EoL care within ARC facilities. This chapter also reviews the limitations of this research, ideas for further research on EoL care within an ARC facility, the significance of this research and chapter conclusion.

Research question

This research set out to answer the question:

'What are the next-of-kin (NOK)/family members' perceptions of the end-of-life (EOL) care provided to their elderly relatives who were residents within aged residential care (ARC) facilities?'

Synthesis of findings

The findings emphasise how the participants needed to share their experience, not only about the last few weeks of their elderly relative's life, but how their elderly relative came to live in the ARC facility, right up to events that took place around their elderly relative's funeral. Their interviews take place like a story, with a beginning and an end. The participants reflect on a sequence of events that include the illness and wellbeing of their elderly family member coming to a crisis point, where changes in their health had determined that they were no longer able, or safe, to live in their current surroundings. The idea of moving into a ARC facility then becomes a 'last resort' where no other option is available and is met with varying degrees of reluctance from the elderly family member. It was the loss of control and independence which the participants used to understand their elderly relative's resistance to the ARC facility, openly explaining how their elderly relative used to be independent, and self-sufficient before their health forced them to consider to life in an ARC facility with round-the-clock care and support.

During the interviews, participants always came back to how much the move to the ARC facility had impacted on their lives and what it had required from them as NoK and/or family member, thus suggesting that this 'new role' they had obtained was central to their experience. They reflected on the personal, emotional and physical measures it took for them to manage the requirements; such as getting their elderly relative assessed, finding an ARC facility, increased time spent with their elderly relative, and tending to the

emotional, and physical needs of their elderly relative. What became apparent through their stories was the expectation and pressure that was placed on them to make the best and right decisions for their elderly relative during the EoL phase, over a long period of time.

Wrapped within their stories of adapting to their new role, participants spoke of how they were challenged when confronting the changes in their elderly relative's personality. They addressed moments when their elderly relative displayed anger, aggression, frustration and low mood, sometimes as a direct result of their illness, the ARC facility, or a combination of the two. The stories they shared also emphasise how difficult and 'testing' these changes in personality were. Their stories suggest that this time became exhausting for them personally and the struggle they had many times, having to just 'handle' and cope with the situation as best they could. Additionally, even within this demanding period, many participants were able to find moments which caused laughter and brief moments of happiness with their elderly relative. These moments reflect ways in which the participants made the most of, and were still able to recognise, small moments of humour amongst other times of demand and challenge.

What partly enabled the participants to get through difficult times during their role as NoK/family member was the care received by the ARC facility. Much of it was reported to be of a high standard, where a relationship was developed

between the ARC facility and the participants. This developed a form of talk that became more comfortable as time went on, but included limited conversation about the details of their elderly relatives EoL care plan. Participants reflected on how the staff provided support that was based on knowledge of who the participant was, who their elderly relative was, which led to more open and honest conversation about the condition of their elderly relative. This finding links to one of the findings from a New Zealand qualitative study addressed earlier, by Marshall et al. (2011), who investigated the perceptions of staff within an ARC facility regarding EoL care. Their participants regarded EoL care, as care that was “dynamic, extraordinary and required special effort” (p. 692). Specifically, their participants commented on how they considered the care of the patient to also include the care of the patients’ family/whanau as well.

Participants advised that the ARC facility staff also dealt with issues regarding their elderly relative quickly and effectively with little request from the participant. Alternatively, on a few occasions participants voiced their dissatisfaction with the ARC facility where their elderly family member resided, and suggested that good service and care was never really displayed to the standard of the participant. This placed even more responsibility and stress on the participant to provide the care that was missing from the staff at the ARC facility. Participants dissatisfaction with the EoL care they experienced within the ARC facility may be further explained by another finding from the study by Marshall et al. (2011).

Their study found that barriers to high quality EoL care within ARC facilities were the resources available; such as lack of staff, heavy workloads and lack of equipment, as well as communication; such as reduced coordination of care, communication and documentation between staff, all which compromise the ability to deliver a high standard of EoL care. Additional to this, a New Zealand based study conducted by Connolly et al. (2014) who investigated the length of time that elderly resided within ARC facilities, and if there was any correlation between the time of first admission, until the time of death. They found that one of the biggest barriers to high-quality EoL care within New Zealand ARC facilities was the incompatibility caused by the high demand of nurses' time, versus limited nursing staff within Auckland ARC facilities.

EoL care discussions between participants and elderly relative were limited to that of funeral plans and arrangements. Participants spoke of the times when their elderly relative had pre-organised their funeral, or had brought up the conversation of what they wanted for their funeral. Some of these participants spoke of how they had found the talk of funeral plans uncomfortable or how the topic was quickly addressed and then put to one side. Interesting enough, in no instance was there a mention of discussions revolving around what care or arrangements they would want should they suffer from an age-related illness, and need a higher level of support and/or medical input. It was clear from the interviews that participants were having to make decisions for the lives of their elderly relative not

knowing for sure what their wishes would have been. These decisions were the cause of much experienced distress and demand during their elderly relative's EoL. The reported produced by the Ministry of Health (2015), highlights the importance of conversations between the patient, their family and health care professionals for EoL care plans and the wants and needs of the patient and their family.

Conversations such as these may have prompted more discussion between the NoK/family member and their elderly relative, and assisted in reducing the strain of the NoK/family member's decision making.

Participants noticed on their own, that their elderly relatives' health was rapidly declining, without the confirmation of ARC facility staff. They spoke of what these signs were; the increase in pain and therefore suffering, the difficulty with breathing, the reduction of energy and coherence. Watching the pain, discomfort and suffering was noted by participants to be one thing they struggled with the most. Many participants spoke of how they did not want their elderly relative to suffer anymore, and how much seeing their elderly relative caused emotional pain on them. It was also noted how the visible gradual decline in their elderly relative's health reduced the unexpectedness of their loss, but began the process of anticipatory grief for the participants, which in some cases occurred from the moment that their elderly relative entered the ARC facility.

Highlighted throughout the interviews was the link between pain and suffering and dying. An important concept here is

how pain and medication were spoken about by the participants; seeing their elderly relative suffering caused participants' emotional pain and struggle, therefore the administration of medication was not only used as a tool to reduce the pain and suffering experienced by the elderly relative, but also to reduce the pain that was felt by the participant from seeing their elderly relative suffer. Participants' involvement regarding the administration and decision-making of medication to use for their elderly relative varied; in some cases' there was open acknowledgment that this domain was placed firmly in the hands of the nursing staff, and administration of medications was organised entirely by the ARC facility nurse. These participants voiced their confidence and dependence in the expertise of the nursing staff within the ARC facility, reflecting on how they were more 'knowledgeable' in the area of medication and more experienced on the how, when and where.

Alternatively, participants personally kept themselves up-to-date on the effect/non-effect the medication/s had on their elderly relative by discussing this with the ARC facility staff, with some mentioning times when they felt that medication disrupted the natural process of death; extending it, and therefore extending the suffering that their elderly relative experienced. The emotional pain experienced by the elderly relative; their talk of wanting to go home, or die, spurred many participants to use methods other than medication in order to reduce their pain such as; spending extended period

of time with them, listening to music, talking, and simply just 'being there'.

Letting go was spoken about as a process that began from the moment their elderly relative entered the ARC facility; understanding that their elderly relative was never coming home and anticipating the day that they would pass away. The realisation was spoken about in terms of loss, grieving for their elderly relative who they were slowly losing. All participants spoke about their grief but some specifically talked of relief, both for themselves and for their elderly relative who was finally at peace. Relief stemmed from a lack of quality-of-life which occurred through the reduction in health and functional abilities, as well as the personal happiness of their elderly relative. This prompted the participants to discuss their views on when their elderly relatives' life had actually ended, versus them passing away. Their stories referred to their elderly relatives lack of ability and activity, and dependency on medical equipment due to a decrease in health and wellbeing. Participants spoke of how this 'reduction' from their elderly relative's former selves, made them realise that life for their elderly relative had ended, even though death had not occurred yet. As mentioned, medications and good quality care were thought to extend life for their elderly relative and some participants shared their indecision as to whether this was beneficial for their elderly relative or not, questioning if prolonging life was worth it, when life is unable to be lived anymore to the same extent.

Participants perceptions of their elderly relative's death reflected their own ideals and values of what they considered to be a 'good death'. This involved a quick, easy death for their elderly relative, with limited pain and to be there with them when they passed away. The New Zealand based study by Marshall et al. (2011) suggested that a significant finding from their study was how the participants did not regard death as a solitary event. Their participants; nurses from ARC facilities within New Zealand, stated that in the event family could not be with the resident, a member of staff would be there with them as they passed away. This also suggests that the idea of 'dying alone' is not limited to this research and extends into further social contexts within New Zealand. Additionally, many participants shared how the actual event of their elderly relative passing and their own ideals did not match up, which had left negative memories of how their elderly relative had passed away and sub-sequential emotional effects on the participants.

In the event of their elderly relative passing away, participants spoke of the thoughts which it had produced regarding death and its processes. The inability to know how they were going to pass away, created a sense of fear for some participants, after having watched their elderly relative go through the unknown processes themselves. This followed on to participants sharing considerations around how they hoped their lives would end, and the extent to which their bodies would start to deteriorate before death occurred. Additionally, many participants spoke of societal processes

of caring for the elderly nearing EoL, displaying romanticised ideas of how it 'should' be and was. Participants stated that ideally, family should play a more focused role in physically care for their elderly family members, as it was 50-60 years ago. They compared this to modern times which has caused a greater demand for ARC facilities due the societies change in family and individual lifestyles.

This highlighted the influence of family relationships, and its ability to shape the experience of death for the participants. They reflected on the effects that family support and care provided not only to the elderly relative, but to the family member/s who are supporting the elderly relative.

Participants emphasised how much the dynamics within their own immediate families affected their experience of the end-of-life of their elderly relative. In some cases, the experience was, although not a nice one, manageable because of the support network that their family provided to them. They could cope because they had someone there to acknowledge their strain and help alleviate it. These findings are supportive of similar findings within a New Zealand study by Bellamy et al. (2014), where participants were interviewed on their experiences of loss and bereavement. Their participants noted how significant family, friends and neighbours were in their ability help them cope and maintain their wellbeing during a difficult time.

Participants within this current study spoke of how much more difficult the whole experience of EoL care became

when they were the sole person to provide emotional, physical and administrative support to their elderly relative. Some participants reflected on times when the demand became so great, that they decided that they could not cope at all, but had no choice but to continue. Many struggled to find time to cater to both the demands of their elderly relative as well as their own personal lives. This increased period of stress and demand seemed to have a significant impact on the participants' experience of EoL care for their elderly relative, and did not reduce until well after the funeral.

The additional demands that occurred after the death of their elderly relative, were discussed by the participants within this study. They reflected on the, sometimes unexpected, extent of funeral arrangements needed to be made so soon after their elderly relative's death, requiring their time, efforts and energy to be pushed even further, all the while going through a process of grief. In many instances, participants spoke of their struggle to cope with the overall demanding process while grieving. And in some instances, participants noted their combined feeling of exhaustion, as well as the relief they felt after the funeral process was over as a final concluding end to their experience.

Limitations

This study has a number of limitations that need to be mentioned. Firstly, it must be acknowledged that the results of this study may not be generalisable to the rest of the New Zealand population. This is because the stories told by the

participants are unique to their own personal experience and can not be extended to others who have been through the similar events. However, there are similarities within each story, and these are the themes presented within this thesis. Additionally, investigating the ethnic perspectives of EoL care in ARC facility was not a focus for this research. Therefore, the results of this research do not draw on themes related to cultural understandings, however the participants' stories are reflective of cultural themes that are related to perspectives from within New Zealand culture and society.

This study takes on the viewpoint of the NoK/family member as to how they perceived the events of their elderly relative's EoL care. It would be incorrect to assume that what they perceived was what their elderly relative went through. Limited studies have used the perspective of the elderly person who is experiencing the EoL care for themselves. Ethical considerations would be at the forefront of issues with conducting this type of research, as well as potential physical difficulties with interviewing such as age-related illness which may alter the elderly participants' ability to respond to questions or initiate conversation in a coherent manner. Many of the participants I talked with told me of their elderly relative's illness and how difficult it was for even them to manage conversation without the interference of medication and its side-effects. However, understanding the NoK/family members experience gives just as much importance to achieving good EoL care, as to that of the elderly person themselves, due to the level of emotional and physical

dedication, and obligation, invested in the process (Ministry of Health, 2015). I am humbled and honored by their willingness to share their stories with me.

Another potential limitation may be the size of this study. A total of eight interviews and 11 participants took part in this research, and is therefore considered a relatively small study. Obtaining more participants may be seen as a way to obtain more data, therefore building and expanding on the results of the study. What had to be considered early on with regards to this research was the time allocated to complete a master's thesis, as well as how many participants would be needed to effectively achieve saturation of the research question. Additionally, the size of the study does not determine its worth, qualitative research has used as little as one or two participants for in-depth interviews in well-constructed research, thus suggesting that the relevance of information shared by the participant/s in a study does not depend on other participant repeating the same idea.

Future research

This research has brought to attention many areas surrounding EoL care for elderly people within ARC facilities that may have not received much attention previously and would benefit from further investigation. This research has highlighted some of the emotional and physical challenges that are included in old age and illness. Further research on what actions have brought elderly to the location of the ARC facility may give more information on

how to keep elderly healthy, safe and active in their own homes. This research has shown that participants included the events before moving into the ARC facility as part of the EoL care of their elderly relative, therefore consideration and research on causal factors that move elderly to the ARC facility may expand on the knowledge we obtain regarding what EoL care is and how it occurs. Additionally, with the slow increase of the elderly population within New Zealand, the more knowledge we consume on age-related illness, how they occur and how they affect those around them, the more we can create health initiatives that aim to keep elderly and their families healthy and safe.

It would be beneficial to understand what part bereavement support plays within the ARC facility to support the residents' families after the elderly resident has passed away. Research conducted by Bellamy et al. (2014) showed that the place of death determined the availability and type of support for the bereaved family. They found that support was more likely to be offered to the bereaved, whose family or friend had passed away within a hospice, compared to those whose family or friend had passed away in an ARC facility or hospital. Additional to this, the current study demonstrates the emotional, stressful decision making and demands that took place when the elderly relative of the participant passed away, as well as the establishment of a relationship between the participants and the ARC facility. Therefore, it may be beneficial to investigate the involvement of the ARC facility, what role they play towards the NoK/family member after

their elderly relative has passed away, and if they are able to provide any mitigating factors to this stressful and demanding time.

Additionally, further research on anticipatory grief for NoK/family members of elderly who reside within ARC facilities, would fill a gap where there is limited literature that investigates this phenomenon, specifically within the context of the ARC facility. It would help to support the current literature on EoL care, and add to know the knowledge of what role anticipatory grief plays within this event for the NoK/family member.

Lastly, future research that focuses on the experiences of Maori NoK/family members' experiences of their elderly relative's EoL care within an ARC facility would build on this current study. Cultural and ethnical awareness for EoL care will become a significant factor as the New Zealand elderly population increases and modern times require the use of ARC facilities country wide.

Significance

The significance of this research is to explore what EoL care actually is, what it encompasses and how it is experienced by the NoK/family member whose elderly relative passed away within this environment. Its significance is to contribute to the literature and expand knowledge for those working with, and caring for, elderly within this context. It is to demonstrate the importance of the NoK/family members' perspective,

giving them an opportunity to share their experiences and perceptions in order to facilitate understanding.

Conclusion

Within this study, EoL care was seen to be a difficult, trying stage that aroused a variety of emotions for the participants who acted as the responsible NoK/family member to their elderly relative. The experience of the ARC facility environment created the perception of an extended period of 'EoL' from the time of admission until the time of death; the NoK/family member was able to acknowledge this move as the 'last stop' for their elderly relative, therefore creating an extended period of grief, responsibility, guilt and loss. It created a time for the NoK/family member to consider what they thought of as a 'good death' for their elderly relative, and also for themselves within the context of the ARC facility. Interestingly, what this study has shown is that EoL care is about so much more to the NoK/family member than just the administration of medication and medical care. Little reference was given to the procedures involved in the EoL care provided within the ARC facility, and more emphasis was placed on the personal, emotive meaning behind the administration of that medication and medical care, how they cope with what the medication does, how the role of staff and family affected their experience, the wishes, the hopes and the needs of how their elderly relative passed away, and how they live their last days within the ARC facility.

Because of the growing population of elderly within New

Zealand, priority should continue with regards to the exploration of what it is to live within an ARC facility, from a multitude of perspectives and cultures, in order to provide continued education and understanding to those who are part of this environment.

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Appendices

Appendix A: Ethical approval letter



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

FILE

29 June 2015

Hayley Barnes
5 Hurley Place
Awapuni
PALMERSTON NORTH

Dear Hayley

**Re: HEC: Southern A Application – 15/38
End-of-life care for elderly within aged residential care facilities: Views and
perceptions from their next-of-kin**

Thank you for your letter received 29 June 2015.

On behalf of the Massey University Human Ethics Committee: Southern A I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Mr Jeremy Hubbard, Chair
Massey University Human Ethics Committee: Southern A

cc Dr Don Baken
School of Psychology
PN320

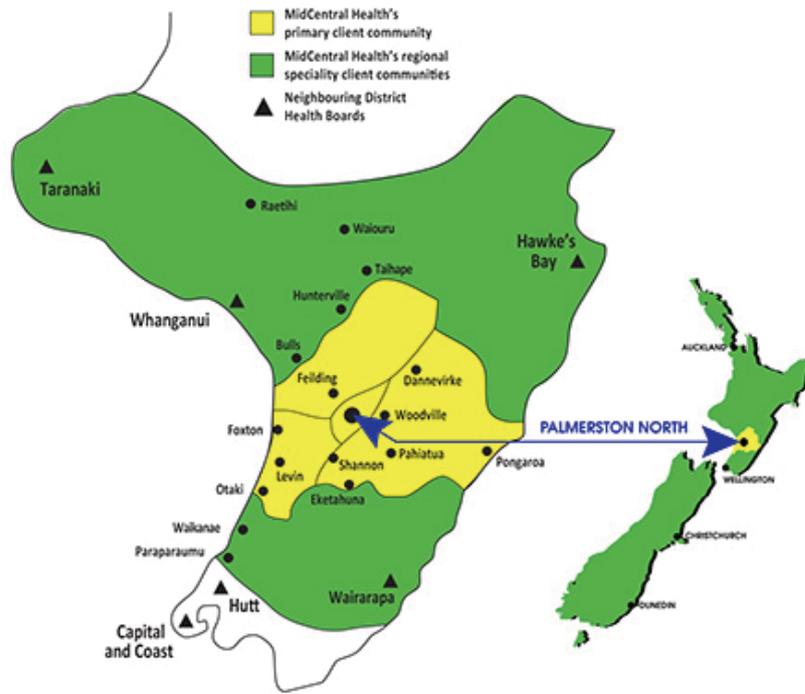
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Appendix B: Map of the MidCentral DHB region



Appendix C: Letter to ARC facility



MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGĀ TANGATA

16th July 2015

Dear _____

I would like to invite you to take part in support of a master's thesis research project that is investigating the end-of-life care for elderly residents in aged residential care (ARC) facilities within the immediate and extended Palmerston North region.

The aim of the research is to explore the experiences, perceptions and expectations of family members and/or next-of-kin (NOK) about the last few days or weeks of their deceased elderly relative while residing in an ARC facility.

In order to contact these family members/NOK as potential participants, organisational support from your facility is central. I am requesting that you use your database to identify the family/NOK of residents who have passed away and make an initial contact to let them know about this study. Potential participants will be family members/NOK of residents who have passed away within the last 2.5 and 5.5 months and resided in either rest home-level care or hospital-level care.

Below is some additional information to tell you more about the background to the research, the potential benefits for conducting this research, as well as answers to some other questions you might have. Please note that participation in this research is completely voluntary and Horowhenua Masonic Village is under no obligation to support this research.

If you have any further information, please do not hesitate to contact me.

Kind regards,

Hayley Barnes
hayleymareebarnes@gmail.com
(021) 1773532

Dr Don Baken (supervisor)
Telephone: +64 (06) 356 9099 ext. 84975
Email: D.M.Baken@massey.ac.nz

Dr Lesley Batten (supervisor)
Telephone: +64 (06) 356 9099 ext. 85094
Email: L.Batten@massey.ac.nz

Te Kūnenga
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The research began when a collaboration between Massey University and Arohanui Hospice became interested in understanding perceptions of death within ARC facilities due to a lack of firsthand information and understanding. Their focus on palliative care and its provision is fundamental to what the Hospice does and the services it provides to dying people and their families of the community. After approaching Massey University to help source this research, Massey University suggested that a scholarship be put together by Arohanui Hospice to invite a master's degree student to carry out the research as part of their course thesis. The researcher selected was a health psychology master's student currently studying at Massey University who had an interest in the health and welfare of elderly people within New Zealand, which was reflected in her part time role as a physiotherapy aide in a retirement home in Gisborne.

Potential Benefits

The benefit of obtaining the perspectives of the family member/NOK on EOL provided by an ARC facility will be a valuable contribution to the knowledge on EOL care for elderly people within our community. Without the investigation of these experiences we may not be able to revisit current models and pathways of EOL care and assess how they measure up to the actual experience of EOL through the reflection of the family members and NOK.

Further Q&A

Q: What am I asking of the ARC facility administrator?

A: To capture the address details of family members/NOK from your database, who live in the Palmerston North area, and who had a family member/NOK pass away that resided in either rest home-level care or hospital-level care between 2.5 and 5.5 months ago. At no time will the researcher have access to the database of the ARC facility. Two letters will be drafted for the family member/NOK, plus an information sheet, inviting them to participate in the research and advising the details of the research. The researcher will draft both letters; one from themselves and one from the ARC facility, and the facility will be able to consider them and discuss any changes they believe would be beneficial. The researcher will provide prepaid envelopes but the administrator would need to place the letters in the envelopes, format the address labels of the family member/NOK for the envelopes and post the letters.

Q: How will the correct family members/NOK be selected using the ARC facility database?

A: The researcher will be unable to utilise the ARC facility database themselves due to ethical and privacy reasons. A checklist will be put together for an ARC administrator to go through the database and selected the residents and their family member/NOK that fit the requirements for the research. If the ARC facility administrator is unsure at any time if a resident and their family member/NOK is suitable for the research they are able to contact the researcher to discuss this at any time.

Q: Who will contact the family member/NOK after sending them the letters and information sheet?

A: No one, the letter from the researcher and the information sheet will have the contact details of the researcher so that those who wish to participate can contact the researcher directly to do so. Those who do not contact the researcher will not be further pursued.

Q: How many people does the research need?

A: We need approximately 10 family members/NOK to take part in the research

Q: How will the ARC facility benefit from this research?

A: A copy of the final report will be supplied to each ARC facility that agrees to support the research. By understanding the perceptions around EOL care; the thoughts, feelings, wants and

needs that EOL care brings about for both the family and the resident, your facility can be part of the goal to further understand EOL care in aged residential facilities in order to make sure that the elderly population of New Zealand are receiving the best care possible during this extremely sensitive and emotional time.

Q: Are there any risks to the ARC facility?

A: There are no harmful risks to the ARC facility for taking part in the research. We are not conducting the research to measure the degree of EOL care that the ARC facility provided against other facilities or any form of criteria. Additionally, the names of the participants and the ARC facilities who do support the research will not be documented at any stage during the final write up and report.

Q: What are the next steps?

A: I will need a letter or email from your facility stating that you will support the research project and have a member of staff access your database on my behalf.

Family Member/Resident Participation Checklist	
Criteria	Yes
Did the resident pass away between 2.5 and 5.5 months ago?	<input type="checkbox"/>
Did the resident reside in hospital-level care and/or rest home-level care?	<input type="checkbox"/>
Did the resident reside in the rest home for a minimum of at least 1 month?	<input type="checkbox"/>
Is the family member/NOK address in Palmerston North or within a one hour radius of Palmerston North?	<input type="checkbox"/>

Appendix D: Letter to potential participant



11th August 2015

Dear Sir/Madam,

I would like to firstly extend my apologies and condolences for the loss of your family member. I can imagine that this must be a difficult time for you and all others involved. The end of a family member's life is always a difficult time, and because of this I have decided to use my thesis research project to understand this time in more depth so that we can better understand what is needed for families to feel supported during a relatives' end of life. I am writing this letter as an invitation to you to take part in a Massey University master's thesis research project which aims to explore your experiences and perceptions of the last few days or weeks of your relatives life while they were in a rest home.

Attached is an information sheet to tell you more about the research, the process involved in the research and what will be involved. I would like to thank you for your time so far, and if you would like to take part in the research, please feel free to contact me via either email or phone before the 25th of August 2015.

If you have any further questions or concerns, please do not hesitate to contact me or my supervisors Dr Lesley Batten and Dr Don Baken.

Kind regards,



Hayley Barnes
hayleymareebarnes@gmail.com
(021) 1773532

Dr Don Baken (supervisor)
Telephone: +64 (06) 356 9099 ext. 84975
Email: D.M.Baken@massey.ac.nz

Dr Lesley Batten (supervisor)
Telephone: +64 (06) 356 9099 ext. 85094
Email: L.Batten@massey.ac.nz

Appendix E: Draft letter from ARC facility to potential participant

Print on ARC facility paper

DATE

PERSONS NAME
ADDRESS
ADDRESS
ADDRESS

Dear Miss/Mrs/Ms/Mr (PERSONS SURNAME)

Firstly we would like to offer our condolences on your loss, we understand this must be a difficult time for you and your family and we are here to offer any further support to help guide you through this time. As part of our dedication to on-going service and educational development and to improve health services within our region, I would like to introduce you to a master's thesis research project that we are supporting which looks to investigate relatives perceptions of the end-of-life care for elderly residents in a number of rest homes within the immediate and extended Palmerston North region.

The other letter enclosed is from the researcher and includes their information sheet which explains the details of the research, what would be required from you as a participant in the research and their contact details if you have any questions or aspects you wish to discuss. We are in full support of this research as we understand the importance of providing excellent end-of-life care to all our residents when that time comes. By supporting research such as this we are allowing further educational achievements to be made, new knowledge to be known, developed and ideas to be created and most importantly, for those who engage in this phase of life, to be heard in a supportive and nurturing manner.

We hope that if possible you choose to participate in this research *however please note that participation in this research is completely voluntary and you are under no obligation to participate in this research.* If you have any further questions, please do not hesitate to contact us.

Kind regards,

(MANAGER NAME)
EMAIL
CONTACT NUMBER

Appendix F: Information sheet



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THE PASSING OF ELDERLY RELATIVES IN RESTHOMES: VIEWS FROM THEIR FAMILY MEMBERS

Information Sheet

Researchers Introduction - Hayley Barnes

My name is Hayley Barnes and I am the researcher conducting this study as part of my master's thesis project in order to complete my Master of Science with an endorsement in Health Psychology. I obtained a Bachelor of Health Science majoring in psychology through Massey University at the end 2013 and have continued my studies due to my interest in age-related research. As an ageing society I think it's important to continue to add new knowledge and information on topics related to ageing and the elderly, especially in New Zealand, and I am fortunate enough to be able to do this through the support of Arohānui Hospice as well as Massey University.



Research Description & Invitation

I would like to invite you to participate in this research which looks to explore your experiences and perceptions of the last few days or weeks of your relatives life while they were in the rest home.

- I would like to meet with you and have a conversation together about this topic, our conversation would take approximately an hour and we could meet somewhere that is convenient for you, either at your home or a private room at the Massey University library.
- I will ask if I can record and take some notes during our conversation
- You are welcome to have whānau/family present during our conversation; they are welcome to contribute to the conversation. The research is about exploring your perceptions as the family member and/or next-of-kind and how you saw the last few days or weeks of your relatives life while they were in the rest home.
- At the end of the conversation a \$20 supermarket voucher will be given as a token of appreciation for your time and for sharing your knowledge with me.

After Our Conversation

- I will type up our conversation and remove your name, any names you mention, the name of the rest home or any other information that may personally identify you. You can choose another name to be used in the research if you wish.
- I will talk to you about reviewing the typed copy of our conversation if you want. If there is any information you would like to add or remove we can do this.

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Private Bag 11222, Palmerston North 4442, New Zealand T 06 356 9099 extn 85701 F 06 355 7966 <http://psychology.massey.ac.nz>

- The recordings and the transcribed conversation will be kept on my laptop which is password protected.
- After the research has finished my supervisor, Don Baken, holds onto the information for a period of five years, after which it is destroyed.

Your Rights as a Participant

You are under no obligation to accept this invitation to take part in the research

- You do not have to answer any particular question
- You may withdrawal from the study at any time up until the time when you have approved the typed conversation with me
- You can ask questions about the study at any time during participation
- You will be given a summary of the project findings when the study has concluded
- You can ask for the recorder to be turned off at any time during the interview

Project Contacts

Please feel free to contact the researcher and/or supervisor(s) if you have any questions about the project.

Researcher: Hayley Barnes
Email: hayleymareebarnes@gmail.com
Mobile: 0211773532

Supervisor: Dr Don Baken
Email: d.m.baken@massey.ac.nz
Contact number: (06) 356 9099 ext 84975

Supervisor: Dr Lesley Batten, Research Centre for Maori Health and Development, Massey University
Email: l.batten@massey.ac.nz
Contact number: (06) 356 9099 ext 85094

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 15/38. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Acting Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicssoutha@massey.ac.nz.

Appendix G: Participant consent form



The passing of elderly relatives in rest homes: Views from their family members

PARTICIPANT CONSENT FORM – INDIVIDUAL

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I agree/do not agree to the researcher taking notes during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:		Date:	
Full Name - printed			

Appendix H: Interview questions

Participant interview preparations

Time duration: approximately one hour

Introduction to participant/mihimihi

My name is Hayley Barnes and I want to firstly offer my condolences for your loss and to thank you again for taking part in this research. I'm from Auckland originally, but lived in Gisborne for a year before moving to Palmerston North at the start of this year. I have been studying with Massey University for five years now and am currently undergoing my Master's degree, which this research is a part of.

Just as a reminder, all your personal details will stay private and confidential, no one will see your names, the name of your relative or the ARC facility where your relative lived. You are welcome to withdraw from the study at any time without having to offer an explanation.

Do you have any questions before we start?

Cultural recognitions

- The bringing of food to the interview
- Mihimihi (as above)
- 'How would you like to begin? Would you like to start with your karakia or I can do one if you prefer?'

Before starting the interview

- Obtain written consent from participant, (their support person or other family members if they wish to participate in the interview); includes ok to record clause
- Explain the recording of the interview; that it can be stopped at any time, and how I will be taking notes and to make sure that this is ok with the participant.
- Start recorder

Interview questions

Background

1. Can you tell me a bit about (relative's name)? How did they come to be in (name of rest home/nursing home)?

Prompts:

- What's your relationship to (relative's name)?
 - What was their occupation?
 - Where did they grow up?
2. Can you tell me about the last few days/weeks of (relative's name) life in (name of rest home/nursing home)?

Prompts:

- Did the rest home discuss the deterioration of (relative's name) health with you?
- What do you remember about them being in (name of rest home/nursing home)?
- What moments sum up your experience of (name of relative) in those last few days/weeks in (name of rest home/nursing home)?

Key factors - Family members/NOK experiences of EOL care

2. Can you describe for me some challenges and/or highlights that you experienced during those last days/weeks (name of relative) was in (name of rest home/nursing home)?

Prompts:

- What was significant about these experiences for you? (*may state the answer to this question as a follow on from question 2*)
- Why do you think these particular experiences come to mind?
- Can you describe an important part of your experience during those last few days/weeks of (name of relative) life, while they were in (name of rest home/nursing home)?
- What areas/parts of (name of rest home/nursing home) helped you through the experience of those last few days/weeks with (name of relative)?

Expectations

3. Can you tell me what you expected during (relative's name) last few days/weeks in (name of rest home/nursing home)? (or) Can you tell me what you expected (relative's name) last few days/weeks to look like while in (name of rest home/nursing home)?

Prompts:

- Why do you think these expectations come to mind? (*may state the answer to this question as a follow on from question 3*)
- Were 'any expectations' (or) 'these expectations,' about those last few days/weeks previously discussed between you and (name of relative)?
- What expectations were most reflected from your experience of those last few days/weeks of (name of relative) life?

Additional information

4. Is there anything else that you would like to share with me in regards to your experience of (relative's name) last few days/weeks?

Additional prompts:

- When you said (.....) what did you mean by that?
- Can you tell me more about that? /experience?
- What happened after that?

End of Interview

Present koha upon finishing

Thank them for their time, and ask if they would like a copy of the transcript; can be sent by either email or mail.

- Explain that the transcript can be given to them to add and/or remove any information from the interview
- After a particular date they are unable to pull their information from the research
- Advise also that they will be sent a copy of the summary of the study at the end of the year, and a link to a copy of the full study if they wish.

Appendix I: Transcript release authority



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AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: _____ Date: _____

Full Name - printed _____