TRANSITION TO END-OF-LIFE IN THE AGED CARE SETTING: IDENTIFYING THE CHANGES.

Submitted by

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STATEMENT OF AUTHORSHIP

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

No parts of this thesis have been submitted towards the award of any other degree or diploma in any other tertiary institution.

No other person's work has been used without due acknowledgment in the main text of the thesis.

All research procedures reported in the thesis received the approval of the relevant Ethics/Safety Committee of the Australian Catholic University.

Signed _____ Ruth Hohn.

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ABBREVIATIONS

ACFI	Aged Care Funding Instrument
AIHW	Australian Institute of Health and Welfare
ABS	Australian Bureau of Statistics
ACSA	Aged and Community Services Australia
AIN	Assistant in Nursing
ANF	Australian Nursing Federation
DEST	Department of Education, Science and Training
DoHA	Department of Health and Aged Care
EN	Enrolled Nurse
EOL	End-of-Life
ACHCP	Aged Care Health Care Personal
HREC	Human Research Ethics Committee
ICP	Integrated Care Pathway
LCP	Liverpool Care Pathway
NPCP	National Palliative Care Program
PCA	Palliative Care Australia
PC	Personal Carer
QNC	Queensland Nursing Council
QNU	Queensland Nurses Union
RACF	Residential Aged Care Facility
RCS	Resident Classification Scale
RN	Registered Nurse
RCNA	Royal College of Nursing Australia
TAFE	Technical and Further Education
WHO	World Health Organisation

GLOSSARY

Abbey Pain Scale: A pain assessment tool developed by Abbey, DeBellis, Pifler, Eaterman, Giles, Parker and Lowcay (2004), to assess pain specifically in the care of people suffering with dementia. This tool does not require the person to answer verbally when asked if they have pain. A series of verbal and physical cues such as moaning or grimacing are used to indicate the person has pain.

Aged Care Health Care Personnel: Nurses who care for people in an aged care facility or nursing home. These nurses include Registered Nurses, Enrolled Nurses and Assistants in Nursing. They have specific knowledge of the care of elderly people who can no longer care for themselves in their own homes. This knowledge includes the life trajectory of elderly people with multiple chronic health needs.

Culture: Culture refers to the way of life of society. It includes codes of manners, dress, language, religion, rituals, expected behaviour such as laws and morality, and belief systems. The culture referred to in this study is the culture of aged care health care personnel.

End-of-Life: End-of-Life is the period immediately preceding death. Many authors define someone as approaching EOL when it is expected that there is only a short period of time before the person is expected to die from a diagnosed terminal condition, even if the time frame is unknown.

Hospice: A model which refers to care aimed at comfort measures rather than the cure for a disease. This model provides support for the person and their family during the terminal phase and after death by way of bereavement care for the family.

Liverpool Care Pathway: A set of care guidelines which was developed by the Royal Liverpool Trust and the Marie Curie Centre in Liverpool in the late 1990's in response to an identified need that the hospice model of care should be translated for use across many care settings including the acute hospital setting as well as the community and aged care settings.

Palliative care: A philosophy which is aimed at providing comfort for the person without the hope of affecting a cure for disease, the aim being to provide the best quality of life possible.

Residential Aged Care Facility: A place where elderly people are cared for when they can no longer be cared for in their own homes, and where they will remain until their death. Their care is usually given by aged care health care personnel which includes Registered Nurses, Enrolled Nurses and Assistant Nurses who are specially trained to care for elderly people. Previously this was referred to as a nursing home.

Resident: This is the name given to a person who resides in a RACF as this becomes their place of residence or their home.

ABSTRACT

The purpose of this research study was to identify the perceptions of aged care health care personnel (ACHCP) working in residential aged care facilities (RACFs) of the changes that indicate a resident has entered the end-of-life (EOL) phase. This is a challenging time for ACHCP because the changes in the resident's condition are frequently subtle and sometimes difficult to identify due to their slow deterioration, often over many months. In order for the best EOL care to be given to residents, timely and accurate assessment of this phase would enable the best possible and most appropriate care to be commenced.

This study utilised a mixed methods methodology and was conducted in two phases. Phase 1 employed a qualitative approach using interviews underpinned by the interpretive paradigm to enable ACHCP to describe the changes that occur when a person being cared for in a RACF enters the final stage of life. In phase 2, the Delphi consensus method was used to confirm two themes that were found in phase 1. A reflective journal was kept throughout the research study by the research student.

The phase 1 findings revealed two themes which provide a rich description of the culture of ACHCP and are described in the domain: *Culture and Context*. Other themes which emerged described two distinct phases that occur sequentially when a resident is close to EOL. The early phase occurs around two weeks before the second or later phase which occurs around one to three days prior to death. Both the early and later phases encompass the EOL phase of care. In each of these phases there are distinct changes that present in relation to the resident's physical status and their engagement with their surroundings. Several of these changes were regarded as clusters and it was felt that for them to be used reliably as indicators of transition to the EOL phase, it was necessary for all to be present. Another theme, *They Get a Certain*

Look About Them is related to the early and later phases of EOL, and collectively, these themes comprise the second domain: *End-of-Life*.

The Delphi method was selected for phase 2 of this research study in which consensus was sought from an expert panel of ACHCP regarding the two EOL phases described in phase 1. A series of statements was developed and offered to the panel of experts in the form of an online survey tool. The level of consensus was set at 75%. Participants agreed that there are two distinct phases which signify to them that a resident being cared for in a high level RACF has entered the EOL phase. There was consensus agreement that there is an early phase around two weeks before a later phase which occurs two to three days before death. The signs associated with the early phase were decreased appetite, increasing frailty and becoming more withdrawn. The signs associated with the later phase were changes to the skin, breathing changes and changes to the circulation. The participants agreed that all of these signs and indicators should be present to confirm the EOL phase.

The findings of this research study have confirmed knowledge from previous research and reinforced the relevance of identification of these two stages for nursing practice in the aged care setting. Specifically, it has confirmed an early phase of change associated with the early signs of EOL. Further, it has refined the traditional signs of the later phase used in other care settings and reinforced signs which are specific to this group, elderly people being cared for in high level RACFs. A reassessment of the current management of the resident and commencement of the most appropriate care based on the early identification of the early phase, around two weeks before the later phase, would enable ACHCP, medical practitioners and family members to initiate interventions that would provide the basis for the most appropriate care at the EOL.

The implications for nursing practice are that a more specific set of signs and indicators which may determine the EOL phase of care for residents being cared for in RACFs. As a way of making this information available to ACHCP, it could be incorporated into educational

programmes and resource material currently available to them, the aim being to promote the best and most appropriate care for residents at the EOL.

The recommendations for future research are to establish the sensitivity of the signs and indicators to determine the early and the later phases and to develop and refine an assessment tool which may be used by ACHCP to confirm the commencement of the EOL phase.

Chapter 1

INTRODUCTION

The purpose of this research study was to identify the perceptions of ACHCP working in a residential aged care facility (RACF), of the changes they observe that indicate a resident has entered the end-of-life (EOL) phase.

Against this background, this chapter provides a picture of the elderly population in Australia, the RACFs in which they are cared for, and the ACHCP who care for them. The chapter concludes with a brief account of the research student as background to this research journey.

The Elderly Population in Australia

The population of Australia is ageing and the impact of this affects all aspects of the social and economic environment [Australian Bureau of Statistics (ABS), 2007a]. People are living longer with complex chronic health conditions requiring more and more intense assistance, over time, from health care providers. It is anticipated that demand for residential aged care services will increase as the population aged 80 years and above increases (ABS, 2007b). While community services provide support for older people to remain in their own homes, over time the complex nature of the care needed requires resources beyond those able to be provided in the community and the person is often admitted to a RACF [Department of Health and Aged Care (DoHA), 2008].

Toward the end of the 19th Century, 4% of people were aged 65 and over (ABS, 2007b). By 2004, this figure increased threefold to 13% (ABS, 2007b). According to the ABS (2007b) in their report on the *Health of Older People in Australia, 2004-2005*, this trend will continue with a prediction that by 2051 this percentage will be 21.3% and by 2101 it will increase to 27%. Those elderly people aged 85 or more will also increase. In 1999, the number of people aged 85 or more constituted 1.3% of the population; in 2004 this number had increased by 1.5% with a prediction of an increase of 5% in 2051 and to eventually total 47% of the

population by 2101 (ABS, 2007b). A report conducted by the Australian Institute of Health and Welfare (AIHW) in 2009 provided an overview of people being cared for in RACFs for the period 2007 to 2008. This report indicated that there had been an increase of 5,401 residential care placements for the twelve month period June 2007 to June 2008 (AIHW, 2009).

The reasons for this changing demographic are linked to advances in medical science and a higher standard of living resulting in increased life expectancy for Australians [Aged and Community Services Australia (ACSA), 2005]. The life expectancy for Australians by 2051 is expected to rise by five to seven years to be 82 for males and 86 for females (ACSA, 2005). The 'baby boomers' whose parents had an average of 3.6 children for each woman, have opted to have fewer children due to greater work commitments and more fertility choices for women. These choices have resulted in relatively fewer young people and a greater percentage of elderly people than at any other time (ACSA, 2005).

People are living longer but have multiple long term health needs which increase with age (ABS, 2007b). In 2005 nearly 100% of people 65 or more reported at least one long term health problem (ABS, 2007b). The main health conditions which affect older Australians are those of the circulatory system (heart disease and strokes) and malignant neoplasms (cancer) (ABS, 2007a). The causes of death in 2004 per 100,000 population aged 65 or more were primarily due to circulatory system (451) and malignant neoplasms (690) (ABS, 2007a). In 2004, of those people aged 85 or more, 6.8% died from diseases of circulatory system and 1.9% from malignant neoplasms (ABS, 2007a).

The implications for this are higher disability and eventual loss of independence which significantly increases as people become older. To remain at home, even with the maximum community services available, becomes difficult and many older people with care needs greater than community services or their families can provide are admitted to a RACF where they are cared for during their remaining years.

Residential Aged Care Facilities

As the population ages, there is an increasing demand being placed on residential and economic services to support the needs of older people (ACSA, 2005). RACFs provide accommodation, personal care and nursing care to people who can no longer care for themselves in their own homes (ACSA, 2007). This care is divided into high and low care facilities, with hostels meeting the low care needs and nursing homes the high care needs. High care needs include full personal and nursing care while low care encompasses mainly supervision with meals and room services provided, while personal care is usually the responsibility of the older person themself.

Data provided by ACSA (2007) indicates that 142,806 people live in RACFs in Australia; 74,148 are in high care accommodation and 68,658 are in low care. A recent report on RACFs in Australia indicates that in 1995 there were 134,810 people in RACFs and this has increased by 40,662 to 175,472 in 2008 (AIHW, 2009). The average length of stay in high care accommodation is 34 months and in low care is 23 months (ACSA, 2007; AIHW, 2009). These statistics suggest that people move into high care from low care accommodation as their needs change and, on average, generally die in a high care facility 32 months from admission into that level of care.

Until March 2008, the Resident Classification Scale (RCS) (ACSA, 2007) was used to determine the care needs of elderly people in RACFs [Department of Health and Aged Care (DoHA), 2010]. The RCS was a needs-based model of classification and rated care needs from 1 being the highest level of care to 8 being the lowest. Care needs were assessed with a series of 20 questions which included categories such as communication, personal hygiene, toileting needs, wandering behaviours, medication and technical or complex care needs. These twenty categories were further subdivided into a four scale ranking which allocated a points systems to the need identified. This was rated from A - needing no assistance to D - needing full assistance with the identified care.

The RCS was used for funding purposes as a subsidy was paid to the RACF by the government for each resident based on this rating (DoHA, 2004; 2006). According to the RCS, in 2004 in Queensland there were 17,574 people with care needs between level 1 and 4 (high care needs) and 8,684 with 5 to 8 (low care needs). In 2006 there were 18,946 people with high care needs and 8,283 with low care needs (DoHA, 2004; 2006). These data illustrate an increase of 1,372 admissions into high care but a decrease of 401 into low care with a total increase of 971 people admitted into aged care facilities over the two year period (Table 1.1). The reason for the decrease may have been due to the previous inconsistent use of the tool by its users (Hogan, 2004), which was one of the reasons the RCS was reviewed.

The RCS was replaced in March 2008 by another funding tool called the Aged Care Funding Instrument (ACFI) (DoHA, 2010). The ACFI aims to better reflect the actual care needs of each resident. Three care domains are used to assess care needs of each resident (DoHA, 2010). The first care domain is called *Activities of Daily Living*. This domain incorporates nutrition, mobility, personal hygiene, toileting and continence. The second domain is *Behaviour* and identifies cognition, wandering, physical and verbal aggression and depression. The third domain is *Complex Health Care* which measures medication management and other complex care needs for instance, wound care. Each care domain is further categorised as having high, medium or low needs based on a scoring system within each domain (DoHA, 2010). The ACFI also identifies diagnoses for each resident which is used to collect data for statistical information and to support any claims made by the care facility.

The ACFI has reported data on residents assessed using this new tool in these categories for 2009. This reflects a significant increase in the number of residents in aged care facilities since data provided in 2006 using the RCS with an increase in 2009 of 1898 residents being assessed as having high care needs using the ACFI tool (Table 1.1). Although these data is difficult to compare as the middle value of medium care needs was not used with the RCS, it provides an overview of the total number of people cared for in RACFs in Queensland for

those time periods. This fact further supports the prediction that the population is living longer and is suffering multiple long term health problems resulting in an inability to be cared for in their homes, as the RCS and the ACFI are used to gauge the care needs of people in RACFs only.

Table 1.1 Resident numbers according to high level care needs in Queensland (DoHA, 2004; 2006; 2010).

Year/RCS Rating	***High (1-4)***	***Medium***	***Low (5-8)***	***Total***
2004	17574	No score	8684	**26258**
2006	18946	Nil score	8283	**27229**
Total increase from 2004-2006	**1372**	Nil	**-401**	**971**
Year/ACFI Rating	***High***	***Medium***	***Low***	
September 2009	20844	n/a	7745	**28589**
Total increase from RCS 2006	**1898**	n/a	**-583**	**1360**

The need to increase the capacity to care for older people in high level RACFs is evident as people age with multiple long term chronic health conditions. More facilities are needed to cater for the high level care needs of these people. Usually, RACFs becomes the final home for elderly people admitted to them. Abbey, Froggatt, Parker and Abbey (2006), in an overview of palliative care in long term care facilities, considered that RACFs are the hospices of the future. The rationale for this statement was based on the notion that almost all residents will die in the RACF as this becomes their final home (Abbey, Froggatt, Parker & Abbey, 2006).

A hospice refers to a philosophy of care for people who are dying which has a focus on their comfort rather than prolonging life [Palliative Care Australia (PCA), 2008; Oxford Concise

Medical Dictionary, 2010]. This could also be applied to the philosophy of care provided for people in RACFs which is also identified as that of palliative care [National Palliative Care Program (NPCP), 2004; Froggatt, McCormack, & Reed, 2006; PCA, 2008]. The ACHCP who care for such people require the particular skills needed to care for elderly residents with chronic long term health needs. This has been recognised as specialised nursing by the Royal College of Nursing Australia (RCNA) in their position statement of *The Role of the Nurse in Palliative Care* (2000). Skills such as management of pain and other symptoms, emotional and spiritual support, and grief and bereavement care (RCNA, 2000) are needed to care for elderly residents, and to support their family, at the EOL.

Skill Mix of Staff in RACFs

In Queensland there are no legislative requirements to establish minimum staff levels, skill mix or specialised training of ACHCP in RACFs [Queensland Nurses Union (QNU), 2004]. The most recent figures available regarding education of ACHCP who work in the aged care setting compares data from a survey conducted for the 2003 period with that from 2007 (Richardson & Martin, 2004; Martin & King, 2008). These reports indicate that the total full time positions of Registered Nurses (RN) in 2003 were 16,265 while in 2007 this decreased to 13,247. The number of Enrolled Nurses (EN) employed in 2003 was 10,945 and this also decreased to 9,856 in 2007. However, the number of Assistants in Nursing (AIN) and Personal Carers (PC) employed rose from 42,942 in 2003 to 50,542 in 2007. The term Personal Carer is one which is used interchangeably with AIN in the aged care setting. This reflects the skill mix of ACHCP working in the aged care setting as there are currently fewer RNs and ENs employed to oversee the work of AIN/PCs as more of these workers are currently employed as the numbers of RNs and ENs decreases.

Training levels were also reported in the survey by Martin and King (2008). They reported that the percentage of AIN/PCs with a Certificate III in Aged Care rose from 54.6% in 2003 to 65.3% in 2007 and that the proportion of AIN/PCs with an added qualification of a Certificate

IV rose from 5.4% in 2003 to 8.8% in 2007. A Certificate III or Certificate IV is a minimum level of training required by most RACFs and provides these workers with basic skills such as providing hygiene cars, feeding and attending to toileting needs of residents in RACF. This training is available through the Technical and Further Education (TAFE) sector which provides educational and vocational training. The post graduate qualification of RNs was also reported and this indicated that in 2003 13.2% of RNs had post graduate qualifications specific to aged care compared with 10.0% in 2007.

Together these data, concerning skill mix and educational preparation, indicate that the number of qualified ACHCP working in aged care is decreasing at the same time as the need for this level of care is increasing. The QNU (2004) stated in their submission to the Senate, *Inquiry into Aged Care*, that aged care providers have not been required to account for the funding they receive from the state governments – there is currently no requirement that aged care providers make available a minimal level of staff to care for older people nor is there a requirement that the mix of staff or training levels of ACHCP be appropriate to the care needs of these residents.

A survey was conducted in 2007 which compared the opinions of RNs in relation to working hours and conditions, professional development and nursing experience (Eley, Hegney, Buikstra, Fallon, Plank & Parker, 2007). This study compared the opinions of RNs with two previous studies conducted three years apart (Healy & Richardson, 2003; Richardson & Martin, 2004). The RNs who were surveyed were currently employed in both public and private aged care facilities and were members of the nurses union in Queensland. The aim of the survey was to provide a picture of the aged care workforce and their working conditions in an effort to highlight the current demand for more aged care provision as the population ages and the need for aged care services increases (Eley et al., 2007).

The results of this survey highlighted nurses' satisfaction with work load and professional development opportunities. In 2001 87.1% and in 2004 85.9% of ACHCP indicated that they

had access to training through their workplace. The barriers to their participation were lack of time, the cost involved, staff to relieve them on the day and distance to travel. However no data was available to indicate the number of ACHCP who undertook this training opportunity compared with those who did not.

Education and training is a way of improving care for older people, increasing job satisfaction and improving retention of specialist aged care nurses (DoHA, 2005). DoHA in conjunction with PCA introduced *The Guidelines for a Palliative Approach in Residential Aged Care* in May 2004 (NPCP, 2004). These guidelines were aimed at providing ACHCP with a comprehensive set of guidelines in which excellent care could be given to all residents in aged care facilities throughout Australia. Although these guidelines were revised and an enhanced edition distributed in May 2006 (NPCP, 2006) a review of the care as a result of the introduction of these guidelines has not been conducted.

DoHA in the National Aged Care Workforce Strategy (2005) recommended training and development of the aged care workforce as a matter of urgency. However, it is unclear from the literature if any further action has been taken in this regard. Although the introduction of the guidelines has provided some direction for ACHCP regarding EOL care, there has been little evidence in the literature to suggest that the effectiveness of the guidelines, as a resource for EOL care in RACFs, has been reviewed or evaluated. Allen, O'Connor, Chapman and Francis (2008), suggest that the implementation has had little impact on care in RACFs. It is difficult therefore to ascertain what level of understanding ACHCP have in relation to this EOL phase for residents in their care. The National Palliative Care Strategy (Commonwealth of Australia, 2000) stated that all people with a life-limiting illness deserve access to high quality care from people who possess appropriate knowledge and skills to care for them. So it may be seen that poor staffing levels and skill mix of aged care nurses and the low rate of specialised training may affect the quality of care for residents with high level care needs at the EOL.

Summary

As the Australian population ages, its impact affects all aspects of the social and economic environment (ABS, 2007a). People are living longer with complex chronic health conditions. As the life expectancy of Australians increases, so does the demand for aged care facilities to house them and qualified carers to meet their care needs. This is further supported by statistical information using both the RCS and the ACFI which highlighted a significant increase in the number of residents admitted to RACFs.

The information which is currently available regarding skill mix and training levels of ACHCP highlights the need to put steps in place to provide Australia's older population with care which is given in the most appropriate way possible, by ACHCP who have the specific qualifications to meet these increasing demands. ACHCP with specialist qualifications in aged care, palliative care and EOL care are needed, ACHCP who are able to recognise the signs of deterioration to a terminal phase, and who will be competent to care for these elderly people until death. In particular, ACHCP should be able to determine when a change has occurred by observing changes in the resident's condition that would indicate that the EOL phase has been reached, thereby enabling appropriate EOL care to be commenced.

Background: The Researcher as an Instrument of Research

In qualitative research, the researcher is frequently described as 'an instrument of research' (Pellet, 2003; Chan, 2005; Freshwater, 2005; Clarke, 2006; McGhee, Marland & Atkinson, 2007). This acknowledges the key role that the researcher plays in shaping the research question or developing the area of inquiry, collecting and analysing data, and the interpretation of findings. The inevitability that the researcher will influence the research process and outcomes is understood in qualitative research. In fact, it is embraced. This is in stark contrast to positivist-rooted research, where any influence brought to bear by the researcher is considered to be bias.

Although, when using qualitative approaches, it would not be appropriate for the researcher to manipulate or falsify their research – this would indeed be considered bias – it is an important part of the audit trail (Northway, 2000; Clark, 2006) for the researcher to be aware of their position in their research process, and how this affects what occurs. Phase 1 of this research study utilised a qualitative design, therefore, it is important for the research student to present an open and honest account of herself, with regard to the context of this research study.

The Research Student: Who Am I?

My background is as a palliative care nurse. I have worked in this capacity for many years and have actively sought ongoing education to enhance my professional skills at both a clinical and academic level. I have a Graduate Diploma in Palliative care and a Masters of Nursing Practice. The care and compassion which I bring to my professional life is also at the core of my beliefs about life as a person. I consider that a person is the sum of their beliefs and their commitment to life is expressed through both words and actions.

In my role as a palliative care nurse, I believe that people should be cared for in the best way possible and that their sense of autonomy should not diminish especially when faced with a life limiting illness. I further believe that people should be enabled to make well informed decisions about their choices for care in relation to the EOL. Their choices should be based on accurate and appropriate information and that my role in this process is to listen to them and empower their decisions.

I was given the opportunity in 2006 to co-ordinate a project which aimed to develop a set of cues which would provide a level of continuity in the care of people toward the end of their life. The aim of this project being that a care pathway would be developed which could be used across many care settings including the hospital, the community (in people homes) and the aged care setting (RACFs). During the trial period for implementation of the care pathway, I became aware of the limitations of its usefulness in aged care facilities, in particular the high level care facilities. When asked to use the cues on the care pathway to identify the terminal

phase for residents in the high level care areas, ACHCP in that area stated that the cues on the care pathway determined that all of the residents in that area were in the terminal phase and had been for some time. Many of the residents had displayed the cues for many months, some for years. This could really not be used to determine the EOL phase for this group of people.

I determined that I would aim to rectify this and if possible to develop a more succinct set of cues which would determine this phase of care for elderly people in RACFs. I had not worked in the aged care setting prior to this time and considered in was in my best interests as a student researcher to gain some experience in this area, to immerse myself in the culture of aged care nursing.

As this experience has evolved, I have realised that this is not different from my role as a community palliative care nurse in that there are more similarities than differences. ACHCP who care for elderly people in RACFs do so with love and great care. They develop firm bonds with them as they often care for them for many years and this includes the EOL phase. ACHCP find this phase of care very difficult as it is like caring for a family member and may be a very sad time for them.

I agree with Abbey et al. (2006) who consider that RACFs are the hospices of the future and who better than a palliative care nurse to facilitate this aspect of aged care. So my commitment to this research project has deepened as I become more immersed in this culture. I consider that the skills and experience I have as a palliative care nurse and the knowledge I have gained from working in this area, hand in hand with the findings from this research study, have provided me with a platform from which I can make a difference in this care setting.

The purpose of this research study was to identify the perceptions of aged care health care personnel (ACHCP) working in residential aged care facilities (RACFs) of the changes that indicate a resident had entered the end-of-life (EOL) phase.

Chapter 2

LITERATURE REVIEW

Introduction

A challenge for RACF ACHCP is to provide terminal care to an increasing number of residents who have a life limiting illness, but deteriorate slowly (NPCP, 2004). Because RACF residents become increasingly frail over a long period of time it is difficult for ACHCP to identify the EOL stage when it is reached and therefore to assess and implement adequate EOL care (Matzo, 2004; Hockley, Dewar & Watson, 2005; Goodridge, Bond, Cameron & McKean, 2005; Porock, Oliver, Zweig, Rantz, Mehr, Madsen & Petroski, 2005; Carlson, 2007; PCA, 2008). Although, in this context, ACHCP do not recognise a resident's death as a failure, they do consider the inability to provide comfort and peace for the dying person as failure (Jack, Gambles, Murphy & Ellershaw, 2003).

This chapter presents a review of the literature regarding EOL care as it relates to the general population and contrasts this with EOL care in the aged care setting. Traditional ways of caring for people at the EOL using care pathways as a way to provide the most appropriate care are also reviewed. The use of these pathways in the palliative care and aged care setting is considered and factors which limit recognition of the EOL stage in the care of the elderly in RACFs are identified.

End-of-Life Care

EOL is the period immediately preceding death. Many authors define someone as approaching EOL when it is expected that there is only a short period of time, perhaps a few days before the person is expected to die (Ellershaw, Smith, Overill, Walker & Alridge, 2001; Hallenbeck, 2003; Ellershaw & Ward, 2003; NPCP, 2004; Watson, Lucas, Hoy & Back, 2009). The decision which determines the EOL stage is made when certain signs are observed. These

signs are discussed later and are outlined in Table 2.1. Traditionally, when these signs are evident it is considered that the person would have between one and three days to live (Ellershaw et al., 2001; Ellershaw & Ward, 2003; NPCP, 2004). The notion that EOL care is confined to the final few days of life is relevant only as it relates to the ability of the health practitioner to put certain activities in place which would enable the best possible care to be provided at that time.

A philosophy of care which is currently being adopted in the aged care setting is that of palliative care. Palliative care refers to a philosophy which is aimed at providing comfort for the person without the hope of affecting a cure for disease, the aim being to provide the best quality of life possible [World Health Organisation (WHO), 2002; NCPC, 2004; 2006; PCA, 2008; Woodruff, 2009]. The NPCP (2004; 2006) has implemented a set of guidelines outlining this in the RACF setting, as discussed earlier. In RACFs the aim of all care is to enable each resident to live the rest of their life without pain and suffering and to provide a supportive environment for them as they enter the EOL phase of care (NPCP, 2004; 2006; Abbey et al., 2006). The notion of providing palliative care is especially relevant in the aged care setting.

The more complex the illness the harder it becomes to determine the time at which the focus should move from cure to care (The Royal Australian College of General Practitioners, 2005). The focus on symptom management is especially important at this time in preparation for the transition to EOL care and death (Hallenbeck, 2003; NPCP, 2004; Murray, Boyd & Sheikh, 2005; NPCP, 2006). Palliative care is a journey which commences with the decision to cease all treatment aimed at curing a disease, and which ends in EOL care and death. Palliative care, then, refers to the time when a cure for a disease is no longer possible and a decision is made to provide active comfort measures for the person and support for their family. This period includes the terminal or EOL phase and the period after death as bereavement support is

traditionally offered to the family. Palliative care therefore, has as its goal, excellent EOL care as this is the end result of the palliative care journey.

The principles of palliative care are especially relevant to care at the EOL. The aim of palliative care is to achieve the best quality of life possible for the person and their family or carer by reducing suffering through early identification, assessment and treatment of pain and other symptoms which may develop (WHO, 2002; Hallenbeck, 2003; Woodruff, 2009). Woodruff (2009) considers the principles of palliative care are to provide a holistic approach with a caring compassionate attitude, to communicate openly and in a professional way with the person, their family and other health professionals and to deliver care which is appropriate to the needs and prognosis of the person. The WHO outlines that the principles of palliative care are to provide relief from pain and other distressing symptoms for people with a life limiting illness; regard death as a normal part of life; affirm the joy of life; intend to neither hasten nor postpone death; inclusive of the psychological and spiritual aspects of care; offers support which help people live with as much quality of life as possible, until death; and includes a support system which helps families cope with grief during the illness and after the death of their loved one (WHO, 2002). These principles are also applicable to care in the EOL, and as mentioned previously, this in the goal of all palliative care.

The final stage of care, which is planned for and incorporated within the provision of palliative care, is referred to as terminal care or EOL care (NPCP, 2004; PCA, 2005; NCPC, 2006). The term terminal or EOL care describes the time when treatment aimed at curing a life limiting disease ceases and the signs mentioned later (Table 2.1) are evident, indicating the terminal or EOL phase. EOL care, then, is the comfort care provided to people which enhances their quality of life, and at all times, being aware that at the end of this journey will be the end of their life. In order for the best care to be implemented at the EOL it is important to be able to identify the signs of this phase and to put appropriate steps in place that would support the transition from the palliative phase to the terminal or EOL phase.

Many residents in RACFs have multiple clinical diagnoses; they need EOL care for a shorter time and may have dementia or other communication problems (Abbey et al., 2006) requiring specialised treatment. Special training regarding the care of residents during the last days of life is very important to support this transition from palliative care to one of support for the resident and their family or carer, as they enter the EOL phase (Abbey et al., 2006; Murray, Kendall, Boyd & Sheikh, 2005; Porock et al., 2005). People with a life-limiting illness deserve access to high quality care delivered by educated and competent staff according to evidence based best practice standards, in a place identified by the person as home (PCA, 2003; NPCP, 2004; PCA, 2005; NPCP, 2006). So it is important that ACHCP are trained in and become competent to deliver EOL care to residents in their homes, the RACF, and to be able to identify the signs when this stage is reached.

Signs that a person will die soon are well documented (Ellershaw et al., 2001; Hallenbeck, 2003; Woodruff, 2009). These signs however, are usually only evident when a person is expected to die from a diagnosed life limiting illness, for example cancer or heart failure. These signs would not be evident if a person has suffered a traumatic incident, or an unexpected death as the result of an accident or acute medical event, such as a myocardial infarction. When a death is expected, the EOL stage is characterised by a slow decline in the level of consciousness as the person slowly seems to go to sleep. It becomes more difficult to wake them and eventually this is not possible; they are unconscious and eventually death occurs.

Information is readily available and easily found which indicates there is a pre-active phase followed by an active phase (Signs of dying, 2007; Death and dying, 2008; Signs and symptoms of approaching death, 2010). The pre-active phase occurs around two weeks before the active phase, around two days before death (Signs of dying, 2007; Death and dying, 2008). Although much of the available information supports this, little research has been conducted which is specific to the aged care setting, in particular elderly people with long term chronic

health conditions, who deteriorate slowly. Porock et al. (2005) conducted a study aimed at developing a model which would predict mortality risk up to six months prior to death. This study indicated that a reasonably accurate model using a point scoring system for demographics, age, sex, disease, clinical signs and symptoms, was helpful in predicting this phase of care.

It is important that criteria which describe the EOL phase are available that enable ACHCP to identify the clinical signs that indicate death may occur for residents in RACFs (Ellershaw et al., 2001; Hallenbeck, 2003; Woodruff, 2009). Early detection of this phase would enable prompt and appropriate care to be commenced that facilitate a peaceful and symptom free death for the resident (Ellershaw et al., 2001; Matzo, 2004; Goodridge et al., 2005; Hockley et al., 2005; Carlson, 2007). This would include: alerting the doctor to the change in condition; having medications reviewed; ceasing unnecessary medications; ordering of more appropriate medications for management of symptoms; ceasing unnecessary tests such as regular temperatures or blood pressure; commencing regular comfort measures such as pressure area care, and regular mouth and eye care, as well as alerting the clergy if appropriate (NPCP, 2004 & 2006).

The opportunity to include the family of the resident in care at this time is another positive aspect of identification of the EOL phase, as this would enable the family to be as involved at this time as they wish to be. Thus, the resident is given the best possible care and the family is able to spend time with the resident, while ACHCP are able to give the most appropriate care based on an accurate assessment of this phase (Murray, Boyd & Skeikh, 2005; Gambles, Stirazker, Jack, & Ellershaw, 2006; Rowley, 2010). Criteria which reflect the signs indicating a terminal phase would provide ACHCP with the opportunity to give the most appropriate EOL care, thus enabling a dignified and symptom free transition to death.

Care Pathways in EOL Care

Best practice in nursing is described as the integration of the best research evidence with clinical consensus (Sackett, Strauss, Richardson, Rosenberg & Haynes, 2000). Fineout-Overholt and Melnyk (2005) suggest that evidence based best practice occurs within nursing by collaboration in clinical decision-making that then leads to the highest quality outcomes for patients and their families. One way to maximise the provision of best practice and evidence based palliative care at the EOL is to use care pathways (Ellershaw et al., 2001; Hockley et al., 2005). A care pathway is a tool which provides a single, comprehensive record for nursing care of a specific group of patients (Jack et al., 2003; Hockley et al., 2005). It acts as a prompt for the care and provides guidance for ACHCP to do certain things at certain times based on best practice standards (Ellershaw et al., 2001; Hockley et al., 2005).

Care pathways have been used to provide evidence based best practice care in the EOL phase (Ellershaw et al., 2001; Jack et al., 2003). They provide a description of the signs which indicate that a terminal stage has been reached (Ellershaw et al., 2001; Hockley et al., 2005). These signs present ACHCP and others providing care with an indicator of a person's deteriorating condition and signal the commencement of the EOL phase. The Liverpool Care Pathway (LCP) for the dying patient was developed by the Royal Liverpool Trust and the Marie Curie Centre in Liverpool in the late 1990s in response to an identified need that the hospice model of care should be translated for use across many care settings including the acute hospital setting as well as the community and aged care settings (Marie Curie Palliative Care Institute, 2010). The hospice model of care refers to care which is aimed at active comfort measures rather than the cure for a life-limiting disease, as discussed previously. An evaluation process is provided which reviews documentation related the care of the person, and questionnaires for nurses and family after death, as a way of evaluating the care. Thus outcomes for the care provided are measured and best practice is maintained in relation to EOL care at the facility.

Criteria were developed, to support the care pathway, which are used by ACHCP to identify this phase of care (Table 2.1). The criteria, or signs, indicate that a terminal stage has been reached and the person will probably die within the next three days, enabling the focus to move to comfort care and symptom management (Ellershaw et al., 2001; Ellershaw, 2001). These signs are described in many articles discussing best practice in EOL care (Ellershaw, 2001; Fowell, Finlay, Johnstone & Minto, 2002; Hall, Schroder & Weaver, 2002; Hallenbeck, 2003; von Guten, 2005; NPCP, 2006). These criteria, however are limiting within the aged care setting, as many elderly people deteriorate slowly, which makes identification of this stage of care difficult for ACHCP (Kafetz, 2002).

Although the criteria identified below (Table 2.1) provide a good indicator of an EOL phase within other care settings such as a hospice or acute hospital, many ACHCP report anecdotally that most of these signs could describe many of the residents in high dependency care and that they have been that way for many years. These include poor oral intake, profound weakness, becoming bed bound, drowsiness and incontinence. These descriptors of the EOL phase, while relevant to most palliative care settings, provide little guidance for ACHCP to initiate EOL care.

Table 2.1 Criteria to identify EOL phase (Ellershaw, 2001, Hallenback, 2003; NPCP, 2006).

- Restlessness or agitation
- Breathing changes - dyspnoea, apnoea and retained secretions
- Increasing pain
- Minimal or no oral intake
- Profound weakness eventually becoming bed bound
- Drowsiness
- Skin changes such as mottling
- Cool extremities
- Incontinence

There are several reports in the literature that identify the use of care pathways for EOL care in aged care facilities in several countries. Partington (2006) described a rollout program in the UK to introduce integrated care pathways (ICP) as the standard practice for EOL care in aged care. She identified that the current format of these pathways needs further work to be useful in the aged care sector as the criteria to identify the signs of the EOL phase are not specific enough for use in this setting. Jones, an ICP Facilitator, and Johnstone, a project manager in a palliative care service in the UK, conducted an evaluation of the implementation of ICP in nursing homes in Wales and concluded that ACHCP in aged care homes find it difficult to recognise the last stages of life and therefore are unable to know when to commence appropriate EOL care (Jones & Johnstone, 2004).

Hockley et al., (2005) assessed the use of an ICP in EOL care in care homes and identified barriers to implementing them. The purpose of their study was to promote quality EOL care in eight nursing homes using an ICP. An action research methodology was used which aimed to identify and promote collaboration between staff in nursing homes when an ICP was implemented. The results from this study indicated that many barriers existed within the culture of these nursing homes which initially prevented the implementation of the ICP. However, the appointment of a nurse in each facility, referred to as a 'key champion', who was delegated to lead this initiative and had specific training to do so, helped both during implementation and subsequently aided its sustainability.

The barriers identified in the study conducted by Hockley et al., (2005) included lack of knowledge about palliative care medications, lack of understanding the signs of the terminal phase and not understanding what happens during the dying phase. The authors concluded that the introduction of the ICP provided ACHCP direction for their care at the EOL for residents as it provided guidelines for identification of the EOL phase and prompts which directed nursing care. The introduction of a key champion nurse provided an educational component and ongoing support for the ACHCP. As a result, the initial barriers were reduced

significantly and ACHCP reported that they were more confident when discussing death and dying, were able to identify this phase, and felt more confident using palliative medications with the introduction of the ICP in their respective facilities. So, it can be seen that identification of this phase provided ACHCP with skills and confidence to deliver care, based on best practice standards by using those identified in the ICP, to residents at the EOL.

Barriers to EOL Care in the Aged Care Setting

Poor educational preparation of ACHCP regarding EOL care is identified in the literature as the main barrier to best practice in EOL care in RACFs. In a South Australian survey of aged care facilities, a questionnaire was completed by directors of 51 RACFs in South Australia, around half in that state (Grbich, Maddocks, Parker, Brown, Willis, Hofmeyer & Piller, 2005). The survey was aimed at measuring the involvement of specialist palliative care services in RACFs. It was reported that up to two thirds of all deaths of RACF residents occurred away from the facility, usually in an acute hospital (Grbich et al., 2005). According to the study, the reasons for this included care needs of the resident beyond the expertise of the RACF staff, which also included the expertise of the general practitioner. They found that RACFs were willing to provide care at the EOL for residents but that staff needed additional support in key areas such as education and further liaison between RACFs and specialist palliative care services in order for this to occur. It has been reported by ACHCP themselves that they are not confident when discussing issues related to death and dying and lack the educational preparation to do so (Grbich et al., 2005; Clark & Ross, 2006).

Clark and Ross (2006) interviewed 24 RNs asking their perceptions and experiences when discussing death and dying with elderly people and identified that these nurses felt poorly prepared, hindering their ability to talk confidently about these issues. Clark and Ross (2006) concluded that fostering a palliative care approach through further education of these ACHCP would promote a better understanding of care at the EOL of elderly people. Phillips, Davidson, Jackson, Kristjanson, Daly and Curran (2006) conducted an Australian wide study

which aimed to describe the perceptions and beliefs about palliative care among ACHCP (RN and EN) and care assistants (AIN/PC) in RACFs. In this study, the ACHCP identified a need for additional education and support about pain management and symptom control as well as the need for further access to specialist palliative care services and resources as important to enhance the care of residents at this time (Phillips et al., 2006).

The evidence suggests that the main barrier which has been identified in the literature to providing EOL care in RACFs is poor education of ACHCP. Poor education includes limited palliative care training, poor assessment of pain, misunderstanding modalities for pain relief, an inability to identify when a resident is dying and poor communication skills when discussing death and dying (Grbich et al., 2005; Clarke & Ross, 2006; Watson, Hockley & Dewar, 2006; Phillips et al., 2006). This view is supported in other studies conducted regarding specific education for ACHCP, as discussed below.

In a review of education and retention of ACHCP in the aged care setting conducted for Department of Education, Science and Training (DEST) it was identified that ACHCP are less motivated to seek ongoing professional education and often do not attend on site education when offered (Pearson & Nay, 2001). A picture of the aged care workforce was provided by Richardson and Martin (2004) and Martin and King (2008) from an Australia wide survey of RACFs. Data was compared with sources from ABS, National Centre of Vocational Education Research and the AIHW. The results indicated that there has been a reduction in the number of RNs who have post graduate qualifications specific to aged care. In 2003, 13.2% of RNs had aged care specific qualifications compared with 10.0% in 2007. This fact is further reflected in a review of nursing education conducted in Australia (DEST, 2002) which indicated that there is a low participation rate of ACHCP enrolling in specialist gerontology courses. Education of ACHCP to provide care specific to this group of people includes education regarding care at the EOL. As has been identified previously, ACHCP are less likely to seek ongoing professional development or tertiary qualifications in the care of elderly

people (Pearson & Nay, 2001; DEST, 2002; Richardson & Martin, 2004; Martin & King, 2008).

Poor education in the care of elderly people at the EOL makes make identification of the EOL phase difficult for ACHCP. Partington (2006), a nurse teacher and nurse practitioner, provided an overview of the many challenges in implementing an ICP in EOL care in RACFs in the UK. She reported that most elderly people in RACFs live and die with many chronic health conditions and as a result the signs indicating they are near death is often not easily noticed. Although the ICP was aimed at providing guidance to ACHCP to identify this stage of care, she suggested that ACHCP and support workers in the aged care setting lack the educational preparation to recognise the signs indicated on this document (Partington, 2006) and that these signs are not specific enough for use in this setting. Criteria specific to elderly residents with high level care needs, which would aid in the identification of the signs of the EOL phase, would facilitate the most appropriate EOL care in RACFs.

Summary

The literature review provided an overview of indicators of the EOL phase currently used in hospital and hospice settings, and the limitations of using them to identify the EOL phase for people in a high level RACFs.

Although care pathways are used by many palliative care providers to provide the most appropriate care at the EOL by facilitating identification of this phase, they are not in common use in RACFs in Australia (Froggatt, Wilson, Justice, MacAdam, Leibovici, Kinch, Thomas & Choi, 2006). There is no standard framework for ACHCP to use which would enable them to identify the EOL phase and to commence appropriate EOL care for residents (Ellershaw, 2001). Gambles et al. (2006) considered that recognition of the signs of a terminal phase would result in the implementation of appropriate EOL care. Abbey et al. (2006) considered that RACFs are the hospices of the future, therefore ACHCP should have the tools which would

enable them to deliver excellent EOL care. Recognition of this phase would enable commencement of the most appropriate care at this time.

Unlike older people in general, the changes in a resident's condition may be very subtle and are therefore difficult to identify, primarily because residents have a slow deterioration over a long period of time (Kafetz, 2002; Ellershaw & Ward, 2003; Froggatt, McCormack & Reed, 2006; Abbey et al., 2006). Many of the signs and symptoms that present relatively acutely when older people in general enter the EOL phase have often been present for a long period of time for RACF residents. Therefore, assessment tools that are based on identification of these signs and symptoms, which have been developed for use with the general population to help determine transition to the EOL phase, are inappropriate for use in the RACF setting.

Therefore, within the setting of a high level RACF, the purpose of this research was to identify the perceptions of ACHCP working in RACFs of the changes that indicate a resident has entered the EOL phase. The intended outcome of this research was to describe and confirm the nature of the changes that occur when a RACF resident enters the EOL phase with the intent that they might be used as points of reference within the existing framework of an assessment tool that could be used by ACHCP.

Chapter 3

METHODOLOGY

This chapter describes the research methods used for this research study. The study utilised a mixed methods approach and was conducted in two phases. Phase 1 utilised a qualitative research methodology underpinned by the interpretive paradigm to enable participants to describe the changes that occur when a resident being cared for in a RACF enters the EOL phase. In phase 2 the Delphi consensus method was used to confirm some key findings from phase 1, which described the transition to the EOL phase.

Although a quantitative method was used in phase 2, this research is based upon an essentially subjective question: How do ACHCP recognise that a resident has entered the EOL phase? This chapter therefore commences with a discussion regarding the interpretive paradigm in which this research is rooted. It is followed by a discussion and rationale for the use of interviews which were underpinned by the interpretive paradigm for data collection in phase 1. Subsequently, the Delphi method, which was used in phase 2, is described and critically evaluated. The specific research processes used in each phase, the findings from each phase and the specific ethical considerations for each phase are presented in chapters 3 and 4.

Research Purpose

As discussed previously, the purpose of this research was to identify the perceptions of ACHCP working in RACFs of the changes that indicate a resident has entered the EOL phase. This can be a challenging aspect of nursing practice because the changes in the resident's condition are frequently subtle and may be difficult to identify (Kafetz, 2002; Ellershaw & Ward, 2003) due to their slow deterioration. ACHCP working in such contexts respond to a variety of signs that are specific to each individual resident, and therefore much of what they do is based upon individual clinical judgement. There is no objective measure

that ACHCP can use to determine that a resident has entered the EOL phase, thus they are reliant on their subjective interpretation of various cues, signs, and changes in each resident's status. To understand better how ACHCP make the clinical judgement about when a resident enters the EOL phase requires a qualitative research approach. It was envisaged that analysis of the findings would help to identify the signs that are present in residents that help to identify the point at which they enter the EOL phase.

Research Design

The interpretive paradigm underpins the world view of qualitative researchers and is concerned with the subjective experience of the person (Burns, 2000; Creswell, 2003; Krauss, 2005). The assessment of a dying person's status and recognition of subtle changes in their condition is an individual process, which is based on both subjective and objective interpretations made by the nurse, who uses clinical reasoning to make an EOL diagnosis which is based on the signs and symptoms that the resident presents.

The research design was therefore an exploratory, descriptive, mixed method, sequential, two phase study. In phase 1, qualitative interviews were conducted. Phase 1 was exploratory and descriptive. In phase 2 the Delphi method was used to quantitatively determine consensus of the views expressed by informants in phase 1. Phase 2 was therefore confirmatory.

Mixed Methods Research

Many researchers describe mixed methods as a valid methodology for conducting research and as a way to maximise the validity and reliability of the data which is collected (Burke-Johnson, 2004; Kelle, 2006). Reliability in research means that the results are predictable regardless of changed circumstances, while validity establishes whether the research methodology selected was able to answer the research question adequately (Streubert Speziale & Rinaldi Carpenter, 2007). Burke-Johnson (2004) stated that mixed method

research is a natural complement to both qualitative and quantitative research and often results in superior data being collected. Mixed method research combines both qualitative and quantitative research methodologies and some researchers consider it a third research methodology (Hammond, 2005; Kelle, 2006).

Often it may be beneficial to combine quantitative and qualitative methods to provide the most accurate picture of a group (Burke-Johnson, 2004; Kelle, 2006; Moule & Goodman, 2009). The purpose of a mixed methods approach is to explain more fully, the richness and complexity of human behaviour by studying it from more than one standpoint as the strengths in one method may be used to support weaknesses in another. For example, a quantitative study which measures, on a predetermined scale, relief from pain using certain modalities could be supported by interviews of the participants which highlight their personal experience of pain. This process would validate the data collected in the quantitative study with qualitative data from the participants' stories. When data are confirmed using a variety of strategies and the findings are consistent, the researcher can be confident in the results, thus maximising validity and reliability.

Phase 1

There are several qualitative methodological approaches that can be used to investigate phenomena that are concerned with human experience. However, the RACF was considered to be a particular context i.e. ACHCP caring for people in a long term residential aged care setting. In this setting, because residents are cared for long-term, ACHCP frequently develop relatively close relationships with them. Also, the way ACHCP work is unique and often ACHCP have worked in the RACF setting for a very long time, developing close relationships with colleagues. These are factors that help to shape the particular group ACHCP in RACFs which is considered by many residents and ACHCP to be more like a home.

Initially, to investigate EOL care within the setting of RACFs, ethnography was considered. However, the most commonly used method of data collection in ethnography is observation; frequently triangulated with interviews and other methods. For ethical reasons, which are discussed later in this chapter, the use of observation was considered inappropriate. Nevertheless, the particular context was considered to be highly relevant to the research area of interest. Therefore interviews underpinned by the interpretive paradigm were conducted, focusing on a particular group setting; in this case the group was ACHCP and the setting was RACFs. For these reasons, and in order to describe the underpinning methodological considerations applied in phase 1, an overview of qualitative research is provided in the following section.

Purpose

Because the purpose of this research project was to identify the perceptions of ACHCP working in RACFs of the changes that indicate a resident has entered the EOL phase, a qualitative approach informed by the interpretative paradigm was chosen. By identification of the care which is appropriate within the RACF setting of participants who care for elderly residents who are dying, the research student aimed to identify the subjective experience of these participants, which captured their *emic* (see below) or insider knowledge that enabled them to identify the EOL phase.

The broad purpose of qualitative research is to understand human experiences. Qualitative researchers consider that humans have the ability to create and shape their own experiences (Polit & Beck, 2006; Robinson & Boyle, 2006; Streubert Speziale & Rinaldi Carpenter, 2007). The aim of qualitative research is to understand this experience by collecting and analysing data from people which is narrative and subjective (Polit & Beck, 2006). Furthermore, it aims to describe interactions within a group as a way of learning about their shared ideas, beliefs and knowledge (Robinson & Boyle, 2006; Streubert Speziale & Rinaldi Carpenter, 2007). Because the purpose of this research project was to identify the

perceptions of ACHCP working in RACFs of the changes that indicate to them that a resident has entered the EOL phase, a qualitative approach has been chosen to inform this research because it best fits the research question.

As noted above, the participant group of interest was ACHCP and the setting was RACFs. A group may be described as one sharing a specific interest, for example a group of surgical nurses, or a group of school teachers. Surgical nurses for example share the experience of caring for people following surgery and their experience is intimately related to this specific knowledge. A school teachers' group is related to teaching students at a school and their shared knowledge is related to teaching skills. Similarly, a group of ACHCP share values and beliefs which enable them to care for elderly people in RACFs.

Perspectives which are used by the qualitative researcher to describe the view of participants are termed the *emic* and the *etic* perspectives (Streubert Speziale & Rinaldi Carpenter, 2007). An *emic* or insider's perspective is a way of describing how members of the group see their own world. This is usually achieved by observation of the group and interviewing its members, validating their views and recording this data accurately. The *etic* perspective, or outsider's view, is that of a non-member of the group and describes and interprets the group activities being observed by them. This is also achieved by observation and interviewing people who have interactions with the group but do not actually do what the group under study does.

The researcher who is also a participant will have an *emic* perspective whereas the researcher who may have some knowledge of the research setting but does not inhabit it, will have an *etic* perspective. Similarly, ACHCP caring for dying patients would have an *emic* perspective of their care, while the relatives of the person being cared for would have an *etic* perspective of the care. Both perspectives may be important for the researcher as a way of providing a complete picture of this particular group and the interactions associated with it.

For the purpose of this research project, the insider perspective or *emic* view was that of ACHCP caring for people in RACFs while the *etic* perspective was noted through the research student's own interpretation of data and experience of having worked for many years in the palliative care setting and more recently, but briefly, in aged care.

Methods of Data Collection in Qualitative Research

Modern day parallels between nursing practice and qualitative research have been described by nursing researchers (Roper & Shapira, 2000). Nursing practice is based on observation of the patient and information about their condition is collected primarily by observation and talking to them. Observation is one of the main methods of data collection in qualitative research (Robertson & Boyle, 2006; Smith & Gallo, 2007; Streubert Speziale & Rinaldi Carpenter, 2007). Participant interviews are another important way that data is collected in qualitative research (Robertson & Boyle, 2006; Smith & Gallo, 2007; Streubert Speziale & Rinaldi Carpenter, 2007). In their day to day nursing practice, nurses use interview techniques to learn how patients and their families are coping and try to maintain a sense of objectivity while caring for people. As a secondary source, to validate their assessment of the patient, nurses utilise other documents including pathology results and test reports and use this information to support their assessment and formulate a plan of care. This is also another aspect of nursing assessment which is shared by qualitative researchers as they use historical documents and other artefacts which are available, to support the data which is collected by observation and interviews (Streubert Speziale & Rinaldi Carpenter, 2007).

Although observation is used to collect data in qualitative research, in this study it was only used as it related to observations made during interviews and personal reflections recorded in a reflective journal. For ethical reasons, it was not considered appropriate to employ observation in this study, as it would be too intrusive for the presence of another person, especially a stranger, at this time (Polit & Beck, 2006). Polit and Beck (2006) state that the researcher has an obligation to protect, not exploit a situation during any research. This

includes the situation related to a dying patient. They further suggest that any observation made during data collection should not include actual family life, for example the care of a dying child by the parents. This is a time when the presence of another person, especially a stranger, would be intrusive and unnecessary and would not add any data to the research process which could not be gained using other data collection methods such as interviewing participants. It would also be difficult to identify the time at which any observations in the field would commence as the trajectory of an elderly person toward the EOL phase is difficult to determine, and in fact is the purpose of this research.

The goal of observation is to learn about the 'true realities' of an experience. Polit and Beck (2006) believe that observation in the field does not always provide the best perspective for the researcher and the 'back stage' approach is suggested by them in certain situations, meaning the view from behind the scenes, not the actual performance of the actor on the stage. This is an excellent analogy for this research project as it was considered by my own experience in the palliative care setting, that any direct observation in the field during this time would be too intrusive to the resident, who is dying, and their family. Streubert Speziale and Rinaldi Carpenter (2007) consider that the best way the researcher can gain the insider or *emic* view is by interviewing group members.

The purpose of this research was to identify the perceptions of ACHCP working in RACFs of the changes that indicate to them a resident has entered the EOL phase. Thus, having excluded use of observation for ethical reasons, the most appropriate method to discover 'true reality' from the group of interest was through the use of the interview.

The Semi-Structured Interview

Interviewing participants is used frequently in qualitative research. Interviews were selected for this research study to enable the researcher to collect data which cannot be observed; the thoughts and feelings of the participants (Sorrell & Redmond, 1995; Streubert Speziale & Rinaldi Carpenter, 2007), but can still focus on a particular group. Interviews which were

conducted were underpinned by the interpretative paradigm as the purpose was to identify the perceptions of a particular group, ACHCP, working in RACFs of changes that indicate a resident has entered the EOL phase, by sharing their stories and experiences of working in this particular setting.

The purpose of conducting a semi-structured interview is to elicit information from participants regarding the values and norms related to their particular group (Sorrell & Redmond, 1995; Kvale & Brinkman, 2008). A semi-structured interview uses a free flowing approach similar to a two way conversation. The researcher, when conducting the interview, responds to information and cues provided by the participant. Sorrell and Redmond (1995) identify the importance of making the purpose of the interview clear to the participant at regular intervals, in particular if the topic of the conversation veers away from the research purpose.

In order to hear the stories of participants, a semi-structured interview was conducted. Semi-structured interviews are conducted with an open framework which allows for a focused, conversational type two-way communication (Kvale & Brinkman, 2008). The researcher aims to build a rapport with the participant and the interview is like a conversation. Semi-structured refers to the fact that not all of the questions are planned ahead of time. Open-ended questions are used, some suggested by the researcher for instance "Tell me about…" and some arise naturally during the interview "You said a moment ago…can you tell me more about that?" The majority of questions are created during the interview, allowing both the interviewer and the person being interviewed the flexibility to ask questions of the other.

The strengths and weaknesses of using semi-structured interviews to collect data are related primarily to the experience of the researcher (Kvale & Brinkman, 2008). One strength of using semi-structured interview is that a positive rapport between the researcher and the participant is established, which as discussed previously, affects the quality of the data collected (Spadley, 1979; Streubert Speziale & Rinaldi Carpenter, 2007; Kvale & Brinkman,

2008). Semi-structured interviews are a simple, efficient and practical way of getting information that may be difficult to observe as participants are encouraged to talk about a subject in detail and depth (Kvale & Brinkman, 2008). The meanings behind an action may be revealed as the participant is encouraged to tell their story with little direction from the researcher. The ability to think of questions during the interview with minimal planning may be a challenge in particular for a novice researcher who may unconsciously give signals or guide a response to a question (Kvale & Brinkman, 2008). Due to the unplanned nature of semi-structured interviews, analysis of data may be difficult, in particular when deciding what is or is not of relevance.

The Interview Process

Interviewing participants relies on the interpersonal skills which the researcher exhibits at the time of the interview and are influenced by subtle emotional and personal characteristics of the researcher (Spadley, 1979; Field & Morse, 1992). If the researcher is able to establish a relationship of trust and confidence with participants at the initial interview, then this will help participants become more relaxed and will be more likely to confide their stories (Spadley, 1979). These skills cannot be learned quickly, and a direct relationship exists between the richness of the data collected and the personality of the researcher.

The way the interview is conducted is important as this influences the quality of the data collected (Streubert Speziale & Rinaldi Carpenter, 2007). Spadley (1979) highlights the importance of entering the interview with respect for the person being interviewed, their history, their culture and the appropriateness of and consideration for issues such as speech and dress (Sorrell & Redmond, 1995; Streubert Speziale & Rinaldi Carpenter, 2007). The researcher should adapt the interview schedule to accommodate each participant and be aware, on the day of the interview, if the participant is not able to be interviewed due to an unforseen event, and reschedule the interview. The interview questions should be aimed at learning from each participant what they believe and know and to understand this from their

perspective. The importance of silence during the interview should also be considered as this is a way to provide enough space for the participant to answer each question openly and honestly. As Streubert Speziale and Rinaldi Carpenter (2007) imply, the nature and intent of an interview is to develop trust and respect as this enables the most accurate representation of the participant's story.

When conducting semi-structured interviews for this research, questions were open-ended as a way of relaxing the participant and helping the interview flow in a more informal manner. The interview progressed with questions which became more focused in response to the participant's comments, and to enable them to fully explore each issue. Each interview was conducted at a place of the participants choosing and at a time most suitable for them. This provided the opportunity for each participant to be more relaxed and at ease, the purpose being to elicit the most complete understanding of their story. However, as identified by Streubert Speziale and Rinaldi Carpenter (2007) during each interview, respect for each participant and awareness that no research is without subjectivity is an important consideration, as the presence of the researcher has a direct influence on the interpretation of the data collected. The researcher becomes the tool for collection and interpretation of all data gathered during an interview.

Data Saturation

Some qualitative researchers continue to collect data until they reach a point of data saturation. Data saturation occurs when the researcher is no longer hearing or seeing new information, and this is the point at which data collection can cease (Guest, Bunce & Johnson, 2006). Unlike quantitative researchers who wait until the end of the study to analyse their data, qualitative researchers analyse data throughout their study, during the interview using reflexivity and also when transcribing the interviews. When data saturation occurs the researcher can be reasonably confident that interviewing additional participants is unlikely to generate any new information.

During the analysis of the data collected from the interviews for this research, it became evident that common themes were emerging after the fifth interview. As a result seven participants were interviewed to indicate data saturation had occurred. It was decided at that point that the interview phase of the research would cease and the common themes which were identified would be offered to the expert panel in phase 2.

Key findings from phase 1 of this research project were used to inform phase 2. Two themes that emerged from the data analysis were used to create a series of statements which informed the Delphi survey which was used to confirm the findings that were specific to the transition to EOL.

Reflexivity and Journaling

During data collection, the researcher should be aware at all times of the influence their presence has on the environment under study as much as the influence that environment has on them. In the literature there is reference to the need for the researcher to be self-aware and to constantly reflect on these considerations (Chan, 2005; Clarke, 2006). Reflexivity is described as the process best suited to this undertaking.

Reflexivity is a way for the researcher to clarify their role and maintain 'objectivity' (Chan, 2005). Chan (2005), when discussing narratives in qualitative research, considered that reflexivity should underscore all aspects of data collection and analysis. The researcher should remain constantly aware of ways in which their presence, as the tool for observation and interpretation, affects the research. This further adds credibility to the research as it highlights aspects of data interpretation for the reader (Chan, 2006), allowing them to make up their own mind about the validity of the research based on their own values and beliefs in relation to that of the researcher.

Reflexivity can improve the quality and rigor in qualitative research (Northway, 2000). The use of reflexivity through a personal diary or journal can provide a clear audit trail by

providing evidence of the influence that the researcher's own values and beliefs had on the data collected and the observations made. It is also important that the researcher be aware of any preconceived notions which could influence what is seen or heard. By reflecting on observations and thoughts during each interview, and using a constant, internal dialogue, or reflexivity, the researcher is able to be more aware of any preconceptions which may be evident in relation to the observations made (Chan, 2005; Freshwater, 2005; Clarke, 2006; McGhee, Marland & Atkinson, 2007). To support this notion, the use of a personal diary or journal, after the event, enables the researcher to develop mindfulness in relation to the influence their presence and their personal views may have on the interpretations made.

During each interview I was very aware that each participant had no understanding of my history either as a credible palliative care nurse or as a novice researcher. The entries in my reflective journal attest to this. Many times I wrote that I felt awkward, that I somehow felt I had to justify why 'I' was there, and that this may have had an impact on the questions I asked. As time progressed, I came to realise that although my professional history may have been relevant as to my credibility, the important thing was my sincerity. I felt that the participants valued the notion that I was there asking these question, sincerely wanting to know the answers and that the information would be valuable to the people they care for. This was humbling and I realised that my ego was not as important as I thought it was. To be sincere and truly present for these participants was the thing I learnt most. As I lost my ego and this was replaced by truly being present during each interview, I realised that each nurse also relaxed and was able to tell me their story.

Reflexivity promotes self-awareness and self-actualisation. This is an opinion held by many researchers in critical appraisals of qualitative research methods (Chan, 2005; Clarke, 2006; Dowling, 2006). The researcher as the tool for data collection is constantly challenged to clarify their own beliefs and values and how they affect the data which is collected. These beliefs and values may change or adapt thus enabling personal growth and an expanded

world view on the part of the researcher. All this information adds to the complete picture of interactions which may affect the participant and the activity which is being investigated. Because the purpose of this research was to identify the perceptions of ACHCP working in RACFs of the changes that indicate to them that a resident has entered the EOL phase, data was collected primarily by interviewing these ACHCP.

Participant Selection

Participants are selected to provide information for a research study and are willing to share their time and knowledge to teach society more about their lives. They should be selected because they have particular insights into the group being studied as members with intimate knowledge of the group interactions and activities and can explain events from different perspectives (Field & Morse, 1992; Roper & Shapira, 2000). For example, participants involved in a study describing the events leading to the death of a loved one, should have experienced the death of a close family member. Participants' involvement in the research study is based on their first hand knowledge and experience in the area of interest to the researcher. In qualitative research participants are selected based on their particular knowledge.

A particular group can be described as the total of the inherited ideas, values, beliefs and knowledge which constitutes the shared basis of a group of people (Roper & Shapira, 2000; Leininger & McFarland, 2006). Components of a particular group include values, norms, artefacts and institutions. Values are the ideas about what is important to the group while norms are the expectations related to certain group behaviours. Both are enforced by laws which keep the group functioning in a predicted way related to those values and norms which are specific to that particular group. Institutions are the structures which also support the values and norms (Australian Oxford Dictionary, 2004). These can be physical structures such as courts of law, municipal buildings or homes. Structures can also be relationships which provide social structure such as employer/employee structures and family structures.

Artefacts are material aspects of the group such as a mode of dress, written material or paintings which relate to the particular group (Roper & Shapira, 2000; Leininger & McFarland, 2006). So a particular group can be described as the learned and shared behaviour which includes belief systems, specific language, social relationships, material goods and institutions specific to the needs of the group.

A particular health carer group can be defined according to these principles. A group of ACHCP who work in a specific area of health share values, norms, institutions and artefacts related specifically to the area of expertise. ACHCP who care for elderly people with multiple chronic health conditions and high level care needs is an example of a particular group. The values they share are those of caring and compassion, and respect for dignity of the person; these are values related to nursing as a profession [Queensland Nursing Council (QNC), 2007]. The norms they share are that they act in accordance with their level of practice or training as ACHCP. This is a law which is enforced by nursing statutory bodies and state legislation (Australian Nursing & Midwifery Council, 2008). Institutions are those aspects related to knowledge and level of training - they are professionally prepared to care for this group of people. Nurses are obliged to meet professional competencies, employer needs and achieve registration requirements within their state (QNC, 2007). The artefacts they share are that they dress in appropriate uniforms which enable them to be identified by the public as nurses, that they are familiar with the documentation expected of their employer to care for their patients, and that they adhere to the philosophy and mission statement of their employer. ACHCP who are employed in high level aged care facilities were the particular group which informed this research.

ACHCP employed in high level aged care facilities are Registered Nurses (RN), Enrolled Nurses (EN) and Assistants in Nursing (AIN) and they form the particular group who were participants in this research. They care for elderly people with multiple, chronic health conditions with high level care needs. High level aged care facilities are those which

provide 24 hour nursing care for residents who are totally dependent for all their needs on those who care for them. These facilities are staffed by RNs, ENs and AINs who provide care to residents over a twenty four hour period. Most of the residents in these facilities have multiple, long term, chronic health conditions and are unable to care for themselves. They require assistance from ACHCP for all activities including medication, hygiene, meals and repositioning in or out of bed. This group was chosen because they have the knowledge and skills relevant to this research – they care for residents who deteriorate slowly. This made them the ideal group to be participants in this research which aims to identify the perceptions of ACHCP working in RACFs of the changes that indicate a resident has entered the EOL phase.

Phase 2

In phase 2, the Delphi consensus method was used to confirm key findings that emerged in phase 1.

Consensus Methods

One strategy used by researchers to maximise validity and reliability is to use a consensus method as a way of confirming the data collected by interviewing participants (Kelle, 2006; Moule & Goodman, 2009). Consensus methods make available a wider range of information by linking the opinions of an expert group to enable decisions to be made or a consensus reached and are increasingly being used to solve problems identified in the health arena (Rolls & Elliott, 2008; Moule & Goodman, 2009). Kelle (2006) stated that using consensus methods can provide confirmation of data and findings as well as a more complete picture of the research than that conducted using one data collection method.

Nominal group analysis and Delphi technique are two methods commonly used in medical, nursing, and health services research to gain a consensus (Kelle, 2006). Nominal group analysis is a structured group process where a group of people, not necessarily experts in a

particular field, are brought together in a face to face group process. There is minimal personal interaction and each member is asked to nominate and rank, on a scale for example from one to ten, what they consider important in relation to the questions presented to the group. The group process is facilitated by the researcher and the information is shared until a consensus has been reached. Another method for gaining a consensus in research is the Delphi technique. The Delphi technique does not involve face to face meetings and uses an expert panel to reach a consensus about a particular research question (Kelle, 2006; Hsu & Sandford, 2007).

Because it is more suited to use with to larger groups and utilises expert opinion, the Delphi technique was selected for phase 2 of this research study, in which consensus was sought from an expert group of ACHCP regarding the phase 1 findings.

The Delphi Technique

A Delphi survey is used to gather data from participants who share a level of expertise in a specific area of practice (Hsu & Sandford, 2007). The method is useful to gain a consensus in nursing research (Keeney, Hasson & McKenna, 2006; Hsu & Sandford, 2007). It has been used by nursing researchers to establish priorities in their research by asking participants to identify and rank the importance of certain research themes (Soanes, Gibson, Bayliss & Hannan, 2000; Griffin-Sobel & Suzzo, 2002; Bond & Bond, 2006).

In the aged care setting a Delphi survey has been used in South Australia asking 51 Directors of Care to identify the extent of specialised palliative care services used by them and the current need for this service (Grbich et al., 2005). It was also used to examine advanced care planning of residents with a non-cancer diagnosis in RACFs in South Australia, conducted with a random survey of 90 aged care facilities (Brown, Grbich, Maddocks, Parker, Roe & Willis, 2007). The purpose at all times is to gain a consensus of opinion about a specific topic from a group of experts in a certain field and is relevant to inform nursing research.

When using the Delphi technique, a series of statements are developed and offered to a panel of 'experts' usually in the form of a survey or a questionnaire. The statements are offered in what is referred to as 'rounds'. These rounds are reviewed and reoffered until a consensus is reached about each statement. The percentage for a consensus can be as low as 51% (Rayens & Hahn, 2000) or as high as 80% (Miller, 2006; Hsu & Sandford, 2007). There is no standard level of a consensus percentage and many researchers suggest that this is generally left to the discretion of the researcher (Keeney, Hasson & McKenna, 2001; Miller, 2006; Hsu & Sandford, 2007). However, a decision regarding this percentage should be decided prior to offering the survey to the panel of experts.

It is considered that a consensus is achieved when a predetermined percentage of agreement is reached by the panel of experts using a median scoring system, generally a Likert scale (Hsu & Sandford, 2007). A Likert scale is a way of ascribing quantitative value to qualitative data, to make it possible to analyse these data statistically, and is widely used in surveys and questionnaires (Colburn, 2003; Kumar, 2005; Sirkin, 2006; Bond & Fox, 2007). It generally uses a five point scale to achieve a level of consensus for a particular statement (Kumar, 2005; Sirkin, 2006; Bond & Fox, 2007). The purpose of a five point rating scale is to offer a neutral value, generally the middle value of 3 on a scale of 1 to 5. This allows participants to choose a middle or neutral value if they consider that they do not have an opinion about a particular statement. Many authors consider that a middle value is not necessary and omit it (Colburn, 2003; Sirkin, 2006; Bond & Fox, 2007). This is termed a 'forced response' where participants are forced to agree or disagree with a statement.

Consensus is achieved using a Likert scale when the percentage of agreement or disagreement falls within two categories on the scale (Hasson & Arnetz, 2005; Hsu & Stanford, 2007). This scale enables the strength of agreement or disagreement of the participant's feelings to be indicated regarding the statement being offered. A Likert scale is easy to use and understand by the researcher and the respondent as the wording used

generally needs little or no explanation (Hasson & Arnetz, 2005). However, it is important to consider the limitations when using this scale. Hasson and Arnetz (2005) advise that the wording used could limit the responses if the description is not adequate or that the number of categories offered may not provide enough choice for participants, forcing them to choose a response which does not really describe their level of consensus.

The strengths and weaknesses of using consensus methods are related primarily to the identification of the expert group. The criteria for selection of the panel is the most important step when developing a Delphi survey as the level of expertise is directly related to the quality of the results (Keeney et al., 2006; Hsu & Sandford, 2007). Other considerations prior to developing the survey are the time frame for completion of each round and the potential low response rate as participants may become discouraged if consequent rounds are lengthy and time consuming to complete.

The advantages of a Delphi survey are that confidentiality is maximised as the participants are not identified individually and that each participant is able to complete the rounds in their own time and without pressure from others. Confidentiality may be helped by a wide geographic distribution which reduces the chance that individuals could be known to one another. Each participant is able to provide insight more thoroughly and clearly in their own time as the pressures on individuals to conform to a group opinion are reduced as no dominant individual is present as is often the case in a focus group (Hsu & Sandford, 2007). Another advantage identified by many authors is that an environment is created in which the expert group are given the best available information thus enabling a consensus to be reached relatively easily (Kelle, 2006; Moule & Goodman, 2009).

Disadvantages of a Delphi survey include the potential for a low response rate, the time needed for completion of each round and potential for disproportionate expertise of participants (Keeney et al., 2006; Hsu & Sandford, 2007). The low response rate may be magnified due to the need for more than one round being sent to the same person, and the

potential for completing the survey may be time consuming. The expertise of the participants may vary as they may have a differing understanding of the statements being offered in each round and differing levels of expertise in the particular area. All these issues should be taken into consideration when developing the survey, however many may be reduced using the Internet to distribute the surveys.

A Delphi survey is distributed to potential participants either manually or by web-based methods. A printed version is distributed manually by direct distribution, by facsimile or by postal service to the participant's address. The disadvantages of a printed version are the cost of printing and postage, the time required handing the surveys out, or addressing and placing them in envelopes and the anonymity of potential participants as personal details are known to the researcher (Bonometti & Tang, 2006).

The use of the Internet is considered an efficient way to distribute surveys (Bonometti & Tang, 2006; Deutskins, Jong, Ruyter & Wetzels, 2006). Online surveys allow for easy distribution to a wide geographical area, are cost effective and easy to create using an already established database. Online surveys are quick for participants to use as a 'one-click' link is used to access the survey, they are fast and easy to distribute to potential participants and personal details of participants are not know to the researcher. The survey developed for this research project was created using existing survey software via *Survey Monkey* ™. In this way, there was little cost involved in creating the survey, distribution was quick and easy for the research student, anonymity of participants was maintained and the results were automatically stored in an Excel database.

According to Hsu and Sandford (2007) the selection of the panel is the most important step when developing a Delphi survey, as discussed previously. The panel should have adequate knowledge and a related background to the area of research. They should be selected from those people who will use the outcomes and come from professional staff members and their support team (Keeney et al., 2006; Hsu & Sandford, 2007). Their selection is usually based

on the discretion of the principal researcher but criteria for their selection should be given careful consideration when developing the survey. The size of the panel for the survey may be variable and can range from ten to as many participants as are generated, but their selection should be as homogenous as possible as this relates directly to the quality of the results which may be obtained (Hsu & Sandford, 2007).

The time frame for completion of the survey is also an important consideration. Panel members can become discouraged with lengthy surveys and less inclined to be part of future rounds. The literature suggests that a minimum of 45 days is needed from creation to analysis for each round with two weeks being allocated for completion of each round of the survey by participants (Kumar, 2005; Miller, 2006; Moule & Goodman, 2009). The precise wording and context for each question is also an important issue as a clear understanding by each panel member of what is being asked is directly related to the quality of the results which are obtained. This is often tested with a pilot group.

A pilot survey is a preliminary piece of research conducted before the final survey is offered to the expert panel (Kumar, 2005). The results of the pilot are not included with the findings of the final study. Pilot surveys can be conducted with a small sample drawn from the same group as will be used for the final survey. The intention of a pilot survey is to alert the researcher to any difficulties that were not anticipated at the survey proposal stage and to pre test wording and phrases to clarify that the researcher and potential participants have the same understanding of the statements in the final survey questionnaire. As a result, problem words, phrases and questions may be edited or completely omitted prior to offering it to the expert panel. This is a way which maximises validity and reliability of the final survey questionnaire (Kumar, 2005).

The validity of a questionnaire relies first and foremost on reliability (Golafshani, 2003). If the questionnaire cannot be shown to be reliable, then there is no validity (Last, 2001; Golafshani, 2003). Reliability refers to the notion that the questionnaire reliably measures

what it was designed to measure, that it is trustworthy and dependable and could be repeated under the same circumstances with the same results (Kimberlin & Winterstein, 2008). This means that statements contained in the questionnaire are clearly understood by the group to be tested and the scale used to measure the results is a valid and predictable scale. Validity means the measurement and assessment of the questionnaire is predictable, sound and derived from already accepted and tested criteria thereby producing a reliable result (Kimberlin & Winterstein, 2008). A Likert scale, as discussed previously, is one such tool which has been shown to be reliable and valid (Golafshani, 2003; Kimberlin & Winterstein, 2008). Therefore, a Likert scale was used when developing the Delphi survey to maximise validity and reliability of the data collected during phase 2 of this research.

Methodology Summary

A mixed methods design was employed for this study comprising qualitative interviews in phase 1 and quantitative consensus in phase 2.

Because the purpose of this research was to identify the perceptions of ACHCP working in RACFs of the changes that indicate a resident has entered the EOL phase, interviews of these participants were conducted using interviews underpinned by the interpretive paradigm. A Delphi survey was selected for phase 2 as it was identified that expert opinion would form the basis for consensus of key findings from phase 1. Themes about the EOL phase of care from Phase 1 were used to formulate statements which were then offered to an expert panel of ACHCP to achieve a consensus in phase 2.

Ethical Considerations

Ethical considerations are important when conducting any form of research and in this instance the research has adhered to the ethical requirements of the National Health and Medical Research Council (2007) and was approved by the Australian Catholic University Human Research Ethics Committee (HREC). Ethics approval was gained for phase 1 of this

research from the Australian Catholic University HREC, register number Q200708 7. Initially this was for the period 21 May 2008 to 31 December 2008 to interview participants (Appendix B). An extension was sought and granted to extend the period for data collection for phase 1 to increase the sample of participants to include five more RACFs. This period was extended to 31 July 2009 (Appendix C). A modification was sought and granted for phase 2 until 31 July 2010 (Appendix D).

Although there are some ethical considerations which were common to both phases 1 and 2, there were also several considerations that were distinct to each phase. For this reason, the ethical considerations which are relevant to each phase of the research are discussed in chapters 4 and 5, which follow.

Chapter 4

Phase 1: Changes Associated with Transition to End-of-Life:

A Qualitative Inquiry

This chapter presents phase 1 of the research study. The research setting and data collection method for this phase are discussed and the findings are presented. Finally, the ethical considerations specific to this phase are identified and discussed.

The purpose of phase 1 of this research was to investigate the understanding of participants within a particular group. The research area of interest was the transition to the EOL phase of elderly residents. Because the participants' understanding is based on their various subjective experiences, the paradigm that was considered to be most appropriate was the interpretative paradigm. As noted in chapter 2, semi-structured interview data collection method was used. Using qualitative semi-structured interviews, and focusing on the research area of interest, the intention was to provide a detailed description of ACHCP shared knowledge to illustrate how participants made sense of their world related to the EOL care of elderly residents in RACFs.

Research Setting

The participants who were interviewed for this research were employed in RACFs located in the Brisbane metropolitan area. Eight RACFs were initially contacted and interviews were conducted with participants from four. All of these facilities provided low level care, high level care and a secure dementia unit, as well as independent living units which enabled residents to be transferred to another level of care as their needs changed, but to remain in the care of that facility. This potentially provided security and comfort for residents as they became known to ACHCP which made this transition easier for them.

The size of the facilities mentioned previously is measured in bed availability. The participants in this phase were employed in RACFs with an average of 40 high level care

beds, 45 low level care beds and 20 dementia care beds. The dementia units were all locked facilities to facilitate safety of the people cared for in this facility. All of the facilities had dedicated respite beds available in their high level and dementia units which provided care for elderly family members on short notice. This enabled carers to have a holiday without committing their family member to permanent care in the facility, with this option if it was needed at a later time. The RACFs were large multistorey buildings with large spacious common areas. Each facility had a relaxed unhurried feel, with warm friendly staff who smiled readily to greet a stranger in their midst. However, this may have been due to the fact it was at weekends when each facility was visited for the purpose of the interviews. All of the facilities had religious affiliations.

The RACFs were staffed by Registered Nurses (RN), Enrolled Nurses (EN) and Assistants in Nursing (AIN) and every facility provided 24 hour nursing care. The normal skill mix of staff in each facility was for one RN and four AINs to be rostered on duty to care for 30 to 40 high care residents during the morning and evening with one RN to oversee the whole facility overnight and two AINs to attend to any nursing care needed during this time, in the high care area, and one AIN in low care. AINs were included in the group in recognition of their significant involvement in the delivery of nursing care to RACF residents under the direction of RNs and ENs. For the purpose of this research when describing the particular group, all ACHCP are hereafter referred to as participants.

Data Collection

Sample Selection

The participants were selected from those currently employed in RACFs in the Brisbane metropolitan area. Five of the participants were employed in facilities in the south of Brisbane and the remaining two were employed in a facility located in the northern suburbs of Brisbane. The criteria for selection, was that the participants were currently employed in a

RACF and had worked in that capacity for more than two years. The criteria included ACHCP at all levels for example, RN, EN, and AIN, who were working in high level RACFs.

The participants described above formed the particular group who took part in this research. All levels of staff who work in this setting were eligible to participate, as they care for elderly people with multiple, chronic health conditions with high level care needs. This group was selected because they had the experiential knowledge and skills relevant to this research as they cared for residents who deteriorate slowly. The care they provided was specific to elderly residents in high level RACFs, affording these ACHCP staff expertise in the care of this group of people. This made them the ideal group to be participants in this research which aimed to identify the perceptions of ACHCP working in RACFs of the changes that indicate a resident has entered the EOL phase.

Recruitment

Participants were selected from those currently employed in RACFs in the Brisbane metropolitan area and who volunteered their time to participate in the research. The names of potential participants were identified from my network of professional colleagues working in this area. This network has been formed over many years in my capacity as a palliative care nurse and more recently in the aged care setting. The names of potential participants were identified and the facility at which they were currently employed prior to any contact with the manager at the facility. The managers of the RACFs were contacted and a generalised letter of permission to interview their nursing staff was obtained, but potential participants were not identified to them. The managers were not informed of the names of the ACHCP. They were provided with an overview of the research study and the purpose for the interviews. It was also clarified with them that the subject matter of the interviews were not related in any way to the organisation and its policies.

Upon receipt of permission from the managers of each facility, the ACHCP were initially contacted by telephone and a letter of introduction was emailed to them with their permission.

It was reinforced to them that their names were not known by their managers and that their consent was completely voluntary. It was also reinforced that there was no pressure on them to consent to be interviewed and if they declined there would be no negative effects such as loss of employment.

The information letter which was sent to them outlined the aims of the research and included a consent form (Appendix A). The letter also clarified that the identity of each participant would remain confidential by use of a pseudonym and any information collected during the interview would be transcribed and given to them to read to clarify that the meaning ascribed to it by the student researcher was what was intended by them. The information letter also contained the contact details of a counsellor if that was needed. It was explained that the consent form would need to be signed prior to the interview with the student researcher.

Upon receipt of this letter the participants read and signed the consent form and returned it indicating their interest in being a participant in the research. They were then contacted by telephone and a suitable time to conduct a formal interview was arranged. With the permission of their manager, the interview was conducted during work time to reduce the impact on their private time.

Participants

In order to protect confidentiality, each participant was assigned a pseudonym. Seven participants were interviewed in phase 1. Five were RNs, one was an EN, and one was an AIN. A summary of their experience in aged care and their professional experience follows.

Amber was an Assistant in Nursing with 12 years experience working in the aged care setting. She had a certificate as a workplace assessor which enabled her to assess workplace health and safety issues. She also had a Certificate III and IV in aged care. She was passionate about her role as an AIN and was insightful as to what she observed on a daily basis when caring for a resident up to and including death.

Brenda was an EN with three years experience in the aged care setting. She had limited experience in any other setting as she had graduated as an EN twelve months prior to her employment in this facility where she had remained for the past three years. As well as her qualification as an EN, she had also done a short course in dementia care.

Cassie was a RN who had worked for 32 years in aged care and previously completed her general training when it was still conducted in the hospital setting. She had also completed psychiatric nursing and felt that this combination was a good groundwork for her role as an ACHCP where many residents had dementia. She had completed a short course in palliative care recently.

Another RN, Debra had worked in aged care for 20 years having completed general and midwifery nursing but preferring the aged care setting after the birth of her children. She had also completed a short course in palliative care. Both Cassie and Debra were enthusiastic when sharing their experience of caring for a resident in the EOL phase.

Enid was a RN who had worked for four years in the aged care setting although she had been an RN for 16 years. She had a degree in nursing, a diploma in education and had attended short courses in management. Her previous work role was as nurse educator in an acute setting and had left this position due to the demands of this role. Fran, an RN, had worked in aged care for 13 years. She had a Graduate Certificate in Palliative Care which she had achieved some years earlier and her intention was to advance this to a Masters of Palliative Care when time permitted.

Gwen, another RN, had worked in aged care for 15 years. Prior to this she had done a refresher course after raising her children. In her previous role, before her break from the workforce, she had worked extensively in the area of burns and plastic surgery and had travelled to England to attend speciality training in this area. She was currently in charge of a Dementia Unit and provided insight from the perspective of residents who are not able to verbalise when in the EOL phase of care.

Interview Setting

The interviews were planned to be conducted on a weekend when the participant was rostered on duty. The choice of conducting the interview on a quiet weekend day in work allocated time and in a quiet room away from the bustle and demands of the work arena enabled participants to be more at ease and focus on the questions being asked. The participant was asked to locate a room away from the work area where the interview could be conducted free from any interruptions which might occur. All participants agreed to be interviewed in their work time and indicated they were not concerned that their anonymity may be compromised, as acknowledged by signing a consent form on the day of the interview. Furthermore, their managers were not informed of the date and time of the interviews. This helped to protect the confidentiality of the participants.

The facilities were easy to locate and parking space was readily available. This was possibly due to the fact that the interviews were conducted on a weekend when staffing was reduced and visitors to the facility were minimal. This made the interview less stressful than it may have been had the facility been difficult to locate and no parking available on arrival. As a result, entry to the facility was as relaxed as it could be. This made the initial contact less stressful for the student researcher and, as a result, the interview was able to commence in a relaxed, less formal way.

The Interview Process

The interviews were informal semi-structured interviews, as discussed in Chapter 2. They were conducted at a time of the participants choosing and during their rostered shift. This reduced the potential impact on the participants' personal life. Each participant was available for at least one hour. The interviews were conducted in a quiet room within the facility and on a quiet weekend day. The door to the room was closed to minimise any risk of being disturbed during the interviews. This provided privacy and a relaxed, intimate atmosphere. Commencing with broad open-ended questions enabled the participants to become more

relaxed as they talked about their past experiences and what circumstances brought them to work in the aged care setting.

The interviews were audio recorded, with additional notes taken in a reflective journal before leaving the facility. This was a way to make certain any thoughts or feelings, which were not evident on the tapes, and any observations made during the interview, were also recorded with pen and paper in a reflective journal. This provided another rich source of data when transcribing the interviews as a way of remembering the context of each interview and any non-verbal cues. Each interview was transcribed within 48 hours of the interview being conducted, and a copy of the transcript sent to each interviewee for verification of meaning. These were returned promptly with no changes needing to be made.

As mentioned previously, it was important for the researcher to establish a relationship of trust and confidence with participants at the initial interview. This helped to provide participants with a relaxed atmosphere, the aim being they may be more likely to confide their stories. To reduce the stress which participants may experience, questions were open-ended as a way of relaxing the participant and helping the interview to commence and flow in a more informal manner. Initial questions were framed around the participants experience and qualifications and they were asked how long they had worked in the aged care setting and what personal or professional decisions bought them to this area of nursing. Some common questions asked initially were:

"You are an aged care nurse. Tell me, how long have you worked in aged care?"

"So you are quite experienced, that's 11 years in aged care. What other aged care facilities have you worked in?"

"So your interest in aged care started all those years ago … what made you stay here?"

As it became obvious that each participant was relaxed and at ease with the interview process, the questions became more focused, and participants were asked to reflect on the care of a

resident who had died recently. All participants were able to reflect on the period leading up to this event.

Data Analysis

A journal was kept by the student researcher to clarify, at a later time, that observations made during the interviews or personal thoughts were also recorded. When transcribing the interviews, this provided another rich source of data and was referred to at all times to clarify that any non-verbal cues were taken into account when transcribing each interview. Each was transcribed by the student researcher to a database, verbatim.

After transcription the interviews were read and re-read until similar themes emerged and these were placed into common groupings. Themes were categorised in two domains: Culture and Context and EOL. Within the domain Culture and Context two similar themes emerged which described Commitment and Professional Satisfaction and Roles and Responsibilities. Within the domain EOL three themes emerged. One theme in the EOL domain described by participants was They Get a Certain Look about Them. Two themes in the EOL domain described the EOL and identified two phases. These were categorised The Early Phase and The Later Phase. A cluster of symptoms which the participants described signifying these phases were labelled 'signs', while another group of symptoms described these signs and were labelled 'indicators'. An example being one sign which signifies the early phase was decreased appetite. The indicators of this sign were described as spitting out food, drooling, poor swallow and profound weight loss. These indicators described the sign of decreased appetite. Several indicators of each sign were identified and these were placed into common groupings. From these common themes a picture emerged of the phases, signs and indicators participants identified which signifies to them that a resident has entered the EOL phase.

The findings from this research provided a description of the culture and context of the RACF setting, a portrayal of the participants themselves, and a description of the transition of elderly residents to the EOL phase.

Findings

The findings revealed two themes that provide a description of the culture and context of the research setting. These are described as Commitment and Professional Satisfaction and Roles and Responsibilities. Collectively, these themes comprise the domain Culture and Context. The remaining themes which emerged from data analysis of the interviews described two distinct phases which signify that a resident has entered the EOL phase. These themes were identified as an Early Phase which occurs two weeks before a Later Phase, around two days before death. The signs describing these phases and several indicators for each sign are also described. Another theme They Get a Certain Look about Them, which is related to the early and later phases of EOL, was described. Collectively, these themes comprise the second domain: End-of-Life. Consistent with qualitative research approaches, these are described in detail below. Verbatim quotes are use to illustrate aspects of the findings and to provide evidence of their authenticity.

Culture and Context

This domain comprises two themes: *Commitment and Professional Satisfaction* and *Roles and Responsibilities.*

Commitment and Professional Satisfaction

All of the participants were very experienced and passionate about their role as ACHCP and indicated that this was a conscious career choice for them. The initial questions were aimed at eliciting information about each participant's background and experience in the aged care setting and included questions about any courses they had attended and any post graduate

qualifications they had achieved. All of the participants spoke freely about their history and shared rich information with the researcher. As Amber shared:

> … what first got me into nursing was I had come to live in the city from [town named] and there was an ad in the paper for a cook and I had worked as a hospitality person, there was an ad for a job at the MS centre and they would train you on the job, so I worked for nearly twelve months and they trained me …

Gwen explained how her nursing training was hospital based and initially her focus was in the acute setting. On her return to her nursing career she found many things had changed:

> Yes, I trained as a nurse in a hospital as we didn't have the uni based training then. I worked a lot in intensive care and then with the burns victims which I loved. Then went over to the UK and did a course in plastic surgery and burns and then carried working in intensive care situations, and then took a break when the children were little. Obviously in that 10 year gap so much had happened that I wasn't a part of that I had to do the refresher course, went into one of the hospitals and stayed there for a year and just didn't like it at all.

Another participant, Debra, outlined that although she worked in the acute setting she preferred aged care. "I did general nursing and I did midwifery and then I came to aged care and I stayed because I liked it." This was further expounded by Gwen who indicated her preference for the aged care setting:

> So I wasn't happy in the hospitals, so I looked around at nursing homes and spent a bit of time working in different ones doing agency work as well going into nursing homes and community. Then I worked (at another facility) for about 6 years and then went back to agency for about another few years and then worked here as agency and decided to stay.

Brenda explained that she also worked in the hospital setting but preferred aged care: "I have been to the hospital as well. I have been here and I feel like this is home for me."

Four of the participants had undertaken short courses related to palliative care in aged care, while one RN had a Graduate Diploma in Palliative Care. Two had completed dementia specific training and one a degree in education and was previously an educator at another hospital before working in the aged care setting. All participants indicated that much of their education was offered in the facility in which they were employed by way of educational

sessions in each facility. They all indicated that this was well received and greatly enhanced their professional understanding of the older person and the needs specific to this nursing role. As Debra indicated: "We do short courses, in house training and sometimes outside …", and further explained the courses offered at the facility: "… they really keep us up to date."

Most of the participants identified that caring for the older person is part of every ACHCP role in every setting. Even in the acute setting, many of the people cared for are older people. Enid stated that: "most of the patients in hospital are older, so you get a good overview." All of the participants had previous experience in the acute setting and reported that they stayed working in aged care because they preferred the more home-like working environment away from the depersonalised atmosphere of the acute setting. All participants reported that this work suited their lifestyle and family commitments. As Anne indicated: "because then I used to work weekends and he [my husband] looked after her [my daughter] instead of having to put her into care. It was suitability where aged care was, and acute care wasn't – not flexible."

The participants spoke easily about their background and why they chose to work in the aged care setting. Most indicated that this was their choice of setting and some intimated that it was their vocation. This potentially provided a relaxed and friendly atmosphere and one which resulted in some laughter at times, further signifying the comfortable environment. Debra shared her opinion about aged care as a preferred nursing situation for her, in particular in the dementia area: "[Aged care is] what do you call it, pure nursing, especially the dementia nursing."

In summary, participants indicated that they were working in the aged care setting as a conscious career choice. They also indicated that they enjoyed the homely setting and found that the care they were able to provide residents was focused on the individual needs of that person because an intimate relationship had developed with that resident over many years. The sense of professional satisfaction was evident by the willingness of participants to pursue

ongoing education both external to the facility in which they worked by way of tertiary qualifications and internally by attending on site education when offered to them. They were proud of their role in this setting and enthusiastic to advance aged care nursing practice by being participants in this research project. All participants were keen to read the results of the research when completed.

Roles and Responsibilities

Participants reported that most daily care of people in RACFs is carried out by AINs who are responsible for basic tasks such as washing, dressing and changing patients, helping them to sit comfortably in chairs and get in and out of bed. They also provide emotional support, talking to residents and families.

In the low care area personal care involves supervision only, with other assistance as indicated by the specific need of the resident. This is usually making of beds and changing bed linen as needed and making sure that residents are in the dining room at the specified times for their meals. Some residents in low care need to have their meals cut up but generally no further assistance with meals than that is required. If the RN or EN is not available at the time AINs who have received relevant education and training are deemed able to do other more advanced duties such as taking a blood sugar level (BSL) for any resident who is a diabetic. This, however, is at all times at the discretion of the RN or EN in charge and provided the AIN is deemed competent by the standards of the facility. In a low care area with 20 residents it is usual for one AIN to be on duty to provide this care, but this is supervised by an RN or EN who may be responsible to oversee 40 or 50 low care residents.

In the high care area, AINs assist residents with all their personal needs including showering, dressing and changing bed linen. Most of the residents require two AINs to assist with this care which could be quite complex. At meal times some residents need to be fed while others can feed themselves if the meal is arranged in front of them. Around half of these residents are taken to the dining room for their meals, but the others remain in their rooms either in bed

or in a reclining chair in their room. As in the low care area, AIN may attend to BSLs as indicated by the RN in charge. It is usual for two AINs to be rostered on duty to care for 20 high care residents, but this is also supervised by an RN. Most of the high care areas have 40 residents where four AINs are rostered on duty with one RN.

Amber saw her role as important to the care of the residents by attending to daily physical cares and reporting changes to their usual condition to the RN, especially in relation to end-of-life care:

> ... because as an RN you don't see that person day in and day out, you don't see the spots on a body and if there are changes, or a lump or swelling because you see them dressed, they open their mouth to take the tablets, you talk to them but you don't know what's going on over there. We are the ones who have got to keep our eyes open and note the changes.

While an EN was in charge on their shift, the ultimate responsibility for all clinical management of a resident was with the RN working in a direct or indirect supervisory position. As a result, the relationship between EN, AIN and RN is important to the decisions made regarding any changes identified in a resident. This was clearly stated by Gwen who indicated that often it is the AINs who alert the RN to changes in the resident's condition:

> Quite often you might feel the temperature, or one of the nurses do, and that's what actually brings you to the resident. They say that so and so has a temperature and you go and look at them and from there suddenly the whole thing kicks in."

The RN relies on the EN or AIN to report changes they note in any resident because if this was overlooked by the AINs the result would be poor clinical management of that resident. If the RN was unaware of an incident which may indicate deterioration in the condition of the resident, and usual comfort activities had been enacted such as repositioning or extra pain relief as per existing organisational protocols, then nothing more would be done to ameliorate that condition. Although ENs and AINs can enact initial management as per the facility protocol, the overall responsibility to review and change the management plan of a resident is with the RN. So trust in the judgement of the AIN is imperative on the part of the RN.

Any change is significant but this is especially relevant if it indicates a change in the usual condition for that resident and one which may indicate a deterioration signifying the EOL phase. Gwen felt that some of the more experienced AINs were quite competent in this role: "The more mature ones, the really good nurses [AINs] who come and tell you there is something not quite right, I think they are really aware." This was reinforced by Amber who indicated that RNs rely on the AINs because: "... we AINs are the ears and eyes for the RNs."

The role of the RN, as described by participants, was supervision of ENs and AINs. Some RNs when on duty handed out medications, attended to wound care, supervised the daily duties of ENs and AINs and problem solved any other issues that arose. This also involved talking with families or other health professionals on behalf of the resident. Fran pointed out: "I have RNs who hand out all the medications and do all the dressings, but any problems, they come to me and I sort out that with them." Part of this care involved talking with families and making sure that their needs were also met especially during the difficult transition to the later phase of care. Debra stated that:

> We [RNs] do the medications, the talking to the relatives, checking whether they need to talk to a pastor or someone like that, we do syringe drivers as part of that [EOL care]. We check if the family need to talk to some other person.

Other more senior RNs completed documentation for funding purposes and problem solved issues related to care of the residents or general management issues, as needed. They also had a large input with families, discussing care and reassuring them as the resident deteriorated. Fran, a care manager pointed out: "I also do a lot of talking with the families as well, you know for anyone who is terminal."

Although participants indicated that they found a lot of professional satisfaction in their role, they were aware that this would become the last home for all residents in their care. That the care provided to these residents will ultimately be EOL care. This was clearly stated by Amber who understood that her role was to provide comfort for the people in her care: "We

are here to see them off comfortably, not to save them." and "You are very comfortable to see them go because you know it is past time that they went. It's nice to see them through that."

It was the ACHCP role to facilitate this in the best way possible, that is by noting the signs of this phase and providing care appropriate to the needs of the resident, at that time. While AINs attended to the physical needs of each resident, they were supervised by RNs. The ultimate responsibility for the care given to any resident was with the RN. It is important that the RN has complete confidence in the ability of AINs and ENs to note any changes which indicate deterioration in the condition of any resident to the RN. Thus it was imperative that RNs, ENs and AINs work as a team with confidence in the ability of each person to accurately assess any change in the usual condition of a resident, their ultimate goal being to provide the most appropriate care at the EOL for the older people in their care.

End-of-Life

This domain is comprised of three themes: *The Early Phase*, *The Later Phase* and *They Get a Certain Look about Them*.

The themes which emerged from the data were described by participants in two distinct phases, a early phase which occurred around two weeks prior to a later phase around three days prior to death. The three signs which confirmed the early phase were decreased appetite, increasing frailty and becoming more withdrawn. The participants described four signs which confirmed the later phase as changes to the skin, breathing changes, changes to the circulation and increasing pain especially on movement. They also described several indicators of each sign. The participants also described how they were able to look at a resident and know a change had occurred: They get a certain look about them. This 'look' was in relation to the early phase and the later phase and was indicative of a 'change' in the resident's usual condition which had occurred.

The Early Phase

It was identified by most of the participants that the EOL phase can be divided into two distinct phases. The participants described the signs confirming a early phase occur at around two weeks prior to death while the signs of a later phase occur around three days prior to death. According to participants, it is extremely difficult to determine when this deterioration might occur. However most suggested that there was a phase which generally occurred around two weeks before death where the resident showed some changes in their usual condition. Some of the participants felt that there was often an event which preceded the deterioration, such as minor surgery or a fall. The event nearly always resulted in a gradual deterioration and eventually death. An example was described by Cassie:

> This is what happened, the poor lady had – she was going on quite stable with all her chronic, chronic conditions she was still mobilising to the dining room and mobilising back and she was really quite medically stable. She had a huge SCC [squamous cell carcinoma] on her head. She was taken to hospital and they did day surgery where they took a skin graft … From then on it was just slowly, it must have knocked everything out of her. When she came back from the hospital that night after the bleed, she looked worn out and tired, and I thought poor thing why do they do this to these old people. I've seen it before, they never have good outcomes it's just the thing that pushes them over the edge.

An event which preceded the deterioration was also described by Brenda: "and at that period she was still mobile and eating well and later on I think she had a fall or something like that."

The participants described the signs of the early phase of deterioration being when a resident would have a decreased appetite, have increased frailty and become more withdrawn. All participants were emphatic that to determine the early phase all these signs must be present as it gives a complete picture of this phase. The participants reported that any one of these signs in isolation was not indicative of this stage. A deceased appetite alone is not enough to determine the early phase. This was reinforced by Enid who pointed out: "And yet you can be wrong too, because people can have an infection like a UTI [urinary tract infection] for example and we try to rule that out obviously, or any other infection."

To determine the early phase the resident would have little or no interest in food or fluids, have lost weight recently as a result of not eating or drinking, be spending more and more time in their bed sleeping most of the day and would not be interested in being involved in any activities or initiating a conversation with ACHCP or family. All of these signs should be present to determine this phase.

Decreased appetite was identified by participants as the best sign of the early stage. Initially this may be evident as a poor swallow or even that the resident may spit out food or fluids, when offered. This would include their usual medications and these were often ceased at this time. Cassie reported that: "[the resident was] having only mouth care, so not tolerating foods or fluids, poor swallow, no oral medications." This was further reinforced when Amber stated: "... he refused any nutrition at all. He would only take a mouthful of fluid. Just wasn't interested in anything" and by Debra when discussing the appetite of a resident at this early phase: "... when they stop swallowing. That's what he did, you know he just couldn't swallow anymore, he kept spitting stuff out and he kept dribbling."

The participants reported that they were unsure whether a reduced appetite was the result of a compromised ability to swallow food and fluids or that it may have been due to just not wanting any food. As Gwen suggested when discussing the early phase:

> [residents were] ... taking minimal amounts of food and fluids. Their swallowing is quite compromised, in that they are either having difficulty swallowing - whether it is a case of not being able physically to get those muscles to work or whether it is a case of remembering that you now have fluid in your mouth and that triggers that you now need to swallow – I don't know. There is certainly something that makes the swallowing difficult.

The inability to swallow was described as a crucial indication of a poor appetite and one which was a sign that a resident was deteriorating and would definitely die soon, as stated by Debra: "... not able to swallow anything at all really. That is certainly a pretty good indicator that is really incompatible with life and they will most certainly die."

The participants were confident that if a resident refused food and fluid, whether it was the result of a poor appetite or the inability to swallow, that weight loss would be evident. They described this as a significant weight loss and one which would be evident as residents are weighed regularly. To maximise their nutritional status, it is important that each resident's weight remains within the parameters of a normal weight / height ratio. Fran reported that often despite best efforts weight loss is significant and not reversible: "Yes, that's definitely the beginning, because we monitor their weights and we give them all supplements, then supplements don't work because they are not eating, it's a vicious circle." This was further reinforced by Fran when she stated that: "… not eating is really the big one. I think weight loss, as we weigh most of the residents monthly we notice that when they have a massive weight loss."

It was reported by participants that a reduced oral intake usually resulted in extreme weight loss indicated by "sunken cheek bones", "pale / ill looking", "a sunken look", "a waxen complexion". Amber described their appearance at this time: "Their cheek bones get a bit prominent and they have lost a lot of weight suddenly, you know they become gaunt." Fran further reported that: "Looking back over the month if they have had a large percentage of weight loss, I can guarantee that they will be dead within a month or two months." Fran also noted that this often seems to happen quite quickly:

> Sometimes one week their skin will look normal and plumped out and then with the decreasing swallow all of a sudden their face will sink in and all the skin particularly around their skull you find that often they are fairly thin, 40 kilo or so, you'll suddenly notice their skin drops away.

It was reported by participants that decreased appetite was definitely the most significant sign that a resident was deteriorating. Participants felt that little oral intake which extended over a few weeks, and not just as an acute event for a few days, was an excellent sign that a change was occurring. The loss of appetite would result in significant weight loss which was evident in physical characteristics which they described as 'sunken cheek bones' and a 'waken

complexion'. Other indicators of this appetite loss were drooling or spitting out food or fluid when it was placed in the residents mouth and an inability to swallow adequately. The participants reported that when they looked at a resident they were able to determine the resident was deteriorating by the way they became pale or ill looking, that their cheek bones seemed to be more prominent and that they had a sunken look about their eyes.

Increased frailty was identified by participants as the second sign in the early phase. Some participants suggested that this may be the result of reduced or no oral intake from a decreased appetite. Indicators of this phase included the resident becoming more bed bound as they became more physically weakened and that their voice became weak and difficult to hear or understand. "Bed bound" is a colloquial term used by many ACHCP meaning that a resident is unable to get out of bed and prefers to remain in bed all day generally because this activity is too exhausting for them. Fran indicted that at this time a resident finds it: "Definitely harder to get out of bed or not wanting to get out of bed." An indicator of increased frailty, the resident's voice becoming weak and difficult to hear or understand, was further supported by Cassie who reported that: "Her voice seemed to have gone, it was like a whisper. A very long hesitated whisper, if she spoke to you it was very quiet and slow." Brenda also agreed that at this time: "[the resident was] speaking very slowly and softly".

The participants indicated that increased frailty was evident when a resident was no longer able to enjoy being out of their bed and remained there, usually sleeping most of the day. In fact it was evident that any excessive movement exhausted the resident and it became clear that the resident was becoming weaker. Although most residents in high care were placed either in a wheelchair or a comfortable lounge chair for periods during the day, as they became weaker their preference changed and they indicated that they wished to remain in the comfort of their bed all day. Often these residents were not taken to the shower but were sponged in their beds as any activity became too demanding on their already depleted energy.

At this time it was often noted that their voice may become almost inaudible. The participants felt that a weakened voice was an indication of their increasing frailty.

Becoming withdrawn was the third sign identified by participants in the early phase. The resident did not want to interact with others by way of conversation and preferred to remain in their bed for extended periods of time. The participants described indicators of becoming more withdrawn were that the resident developed a vacant or faraway look, no longer recognised familiar people and had limited or no verbal interaction with others. The participants indicated that this change was quite significant and generally a considerable change in the resident's usual behaviour. Amber indicated that although usually this resident enjoyed a joke or a laugh with staff, at this time: "He just wanted to be left alone." Gwen described this when she noted:

> She just curled into herself, the eyes were still open and there was a little bit of recognition there, but there just wasn't the same aura about her. I said to a couple of the nurses, I wouldn't be surprised if she is gone before Christmas.

Becoming withdrawn was described perfectly by Gwen when she observed: "They are more withdrawn, physically they might turn into themselves with their arms for instance.", and on further reflection she stated:

> I find quite often when they are in that dying process, there is almost a distance in their eyes, almost a faraway look. They are not focusing at all on what you are saying or what is around them. They are focusing on something faraway. And there is usually a peace about them and that sometimes changes - a stillness.

In summary, it was agreed by the participants that all of these signs should be present, not one in isolation, to consider an early phase. The participants described that the first sign of this phase which would alert them to a change was that the resident would refuse food and have only small amounts of fluid. Often the resident may be unable to swallow or that they may spit out food or fluids or even drool when this was placed in their mouth. This appetite loss would become more obvious over a few weeks when the resident had an extreme weight loss

being evident in physical signs such as ‘sunken cheek bones’, ‘a waxen complexion’ and a ‘pale / ill look’.

As a result of this weight loss participants described increased frailty as the second sign of the early phase. This meant that a resident who was previously able to spend time out of bed during the day was no longer able to do this and found it too exhausting. The resident preferred to remain in bed usually sleeping much of the day as they became weaker. The participants described the third sign of this phase was becoming more withdrawn where a resident who once enjoyed a joke and often initiated a conversation, no longer did this. As described by Amber: “… and he lost the willingness to have a little joke or a little laugh or fun like he had. He was always a fighter. If he could get you to argue or fight back that would make his day because that was what he was like – he used to egg me on all the time.”

The resident remained withdrawn, seeming to be in their own world with little or no interaction with others, often not seeming as if they recognise familiar people, with a vacant look in their eyes. The participants considered that all three signs should be present to determine the early phase around two weeks prior to the later phase.

The Later Phase

The participants stated that the transition to the later phase was always preceded by the early phase, as described above. Participants described the signs of this transition were skin changes, signs of circulation shut down, breathing changes and pain on movement.

Skin changes were a sign of the later phase. Participants stated that no matter how often the resident was repositioned, their skin was marked on the side on which the resident was lying, this being a good indicator of skin changes. Another indicator of skin changes was a mottled appearance to the skin. The skin of the resident would have a blotchy, purple appearance particularly on the dependent side or the side on which the resident was lying. Amber

indicated that she observed this and stated: “Yes, he marked very easily. He had been marking all that week.”

Signs of circulatory shut down were another sign of the later phase. This meant that there was bluish discolouration or cyanosis of the feet, hands, and often the ears. The skin had a dusky, grey appearance. Once again this was described by Amber when she noted: “I gave him a wash and I noticed his feet were very dusky around his toes and discolouration.” She described the appearance at a later time that day: “So I checked his feet again and again the dusking was there, but this time it was more prominent and there was mottling coming.” Mottling referred to the bluish discolouration described earlier.

Breathing changes were another sign of the later phase. The participants indicated that often the resident would develop noisy rattly breathing which could be very distressing to the family and often also the ACHCP caring for the resident at this time. This was described by Debra: “In the last three days we gave him morphine because he had the dyspnoea and he was Cheyne-Stokes breathing for about three days.” Amber reflected and stated: “he’d go into a very deep sleep and you almost couldn’t see him breathing, very swallow breath, very shallow.”

Increasing pain on movement was also described by participants as a sign of this later phase. Participants reported that this occurs in many residents during this time as described by Fran who stated: “Also increased pain. So what we started off with her was increasing ordine [morphine taken orally] before cares because she was still swallowing.” Increasing pain on movement was evident when ACHCP were caring for the resident and was usually not present when the resident was resting undisturbed. The resident, although often unconscious or deeply asleep would grimace or moan when being repositioned indicating to the ACHCP that the movement was painful as reported by Cassie: “She was experiencing some pain, only when we were tending to cares, but not when she was sitting comfortable with the oxygen on. Then she was not in pain.

Enid indicated that in her opinion regular pain relief should be given before attending to any care such as repositioning or sponging the resident to prevent any unnecessary discomfort. She also alluded to the fact that some of her colleagues do not administer pain relief appropriately and stated that: "I guess another thing is my colleagues hold back and assess the resident's pain when they are just lying there when nothing is being done for them. They should be giving them morphine before their cares are done." Gwen agreed that pain relief should be given as ordered by the Medical Practitioner especially if the resident displayed signs of discomfort when she stated:

> If they were restless then, for me that would be very clear indicator of pain. That's when I would give them the maximum amount of pain relief. But if they are lying quietly and there aren't any signs – I guess you have to know the resident to determine if that is withdrawing because of pain or is that contentment.

Gwen described the need to have a more formalised assessment process for determining pain in this setting and indicated that the experience of the ACHCP had a significant impact on the accurate assessment of pain at this time. She also indicated that although the Abbey Pain Scale is an excellent tool for determining pain in the dementia setting, she felt that this was tempered at all times by the experience of the ACHCP using it and dependent of their understanding of how to apply it in this setting. She stated that:

> This is an area that causes us probably the most amount of anxiety as nursing staff because all of us have a different opinion as to whether there is pain or not. I find that although the Abbey Pain Scale is great for dementia residents, I personally don't think it is very informative for the end-of-life for us nurses who have come from such a wide background. So many of us are hospital trained, some of us have kept up our skills by going to seminars and conferences, but there is an awful lot who haven't.

The participants described the later phase as being preceded by the early phase. The later phase usually occurred much closer to death. The time frame indicated by the participants ranged from one to three days before death. They described the signs of this phase indicated by skin changes evident when the resident was repositioned where the area on which they were lying appeared blanched or had a mottled appearance; signs of circulation shut down

where the resident's skin had a bluish discolouration, especially at the extremities; breathing changes including periods of no breathing, shortness of breath and noisy rattly breathing; and increasing pain when the resident was repositioned. If all of these signs were present, participants indicated that they were certain that the resident would die in the next few days. Amber reflected on this time and stated: "There so many little things that happen and you think ... you can't put them in a sequence, it's just something you are looking at." This was reinforced when Enid also considered that the combination of all of the signs were what gave the most accurate picture: "Yes, the combination of things, yes for sure."

In summary, participants described the early phase as commencing around two weeks before the later phase, which commenced one to three days before death. They indicated that all the signs of the early phase needed to be present, followed by all the signs of the later phase, and that one sign in isolation would not be adequate to determine the transition to the EOL phase as this provided them with the complete picture.

They Get a Certain Look about Them

Many of the participants identified that they could look at a resident one day and know that they would probably die soon. They stated that they knew a resident would die soon and reported this was due to the fact that they had many years' experience in the aged care setting and that they had cared for that person for a long time and knew them well, which enabled even the smallest changes to be noticed. Fran explained: "It is one of those hard things when you walk in [to the room] and say to yourself that you [the resident] are not going to be here much longer." Debra also reflected on this time as a resident deteriorated and stated: "You suddenly look at them one day and think, Oh." Gwen agreed that there is a "certain look" about the resident and that there is a certain feeling which cannot be easily described but which signals to her that a resident may die soon:

> I guess the main thing, and this is where it is so difficult to put it all down in words, I guess the main thing is that they get a look about them. There is just a feeling and

> there's just a look about them and that's what's difficult to try to describe to anyone else.

The close relationship which develops over many years resulted in an intimate understanding of what is usual for a particular resident. This made detection of any lasting changes in the usual condition of a resident less difficult. When alerted, the RN was able to assess that a deterioration had occurred which may indicate the commencement of the EOL phase. Although experience of the participants enabled this diagnosis to be made, this was an informal cue for this to occur as often these signs may be overlooked by less experienced nursing staff or nursing staff who have a less intimate relationship with a resident. A more formalised set of signs and indicators signifying these phases would enable ACHCP to accurately diagnose the EOL stage for a resident, enabling the most appropriate care to be commenced.

Summary of Phase 1 Findings

Seven participants were interviewed and their experience in the aged care setting ranged from three to 32 years. Most of the participants indicated that they preferred the aged care setting as it was more of a home-like environment and the conditions suited their family and lifestyle commitments. Participants described their commitment and professional satisfaction and were passionate about their role as ACHCP. They described their roles and responsibilities and the importance of working as a team within the culture of RACFs, with confidence in each person's ability to recognise the changing needs of residents especially in the transition to the EOL phase.

The participants described two distinct phases that could be identified which indicated that a resident was deteriorating and would probably die soon. These phases were described as an early phase which commenced around two weeks prior to a later phase, which usually commenced around three days before death. Signs of the early phase were decreased appetite, increased frailty and becoming more withdrawn. Signs of the later phase were skin changes,

signs of circulation shut down, breathing changes and increased pain on movement. The participants considered that all of the signs of these two distinct phases should be present for the diagnosis of a later phase of care. The participants also reported that they could look at a resident and know that something was different and a significant change had occurred. They stated that residents "get a certain look about them." Participants reported that this was difficult to put into words, but that it added to the complete picture for them and was another way which confirmed the commencement of the EOL phase.

Phase 1 Ethical Considerations

The student researcher has respected the premise that no harm is done is an important aspect of research especially when dealing with people's feeling and opinions as this is when humans may be at their most vulnerable (Mauthner, Birch, Jessop & Miller, 2002; Australian Government, 2007). No harm or exploitation of the group, or their opinions, occurred (Australian Government, 2007). The recommendation by Roper and Shapira (2000) is to make the intent of the research clear to the participants at each interaction and to respect privacy and confidentiality of those involved as well as providing fully informed consent for participants. This was taken up in this study and as can be seen in the following discussion, all care and attention was given as advised during every stage.

Prior to commencement of data collection for phase 1 of this research, participants were given information about the research which was conducted at their facility in the information letter (Appendix A). This highlighted the need to sign a consent form (Appendix A) prior to the initial interview. At commencement of the initial interview, the research process was explained again and the consent form signed by the participant. The participant was reassured that they were free to withdraw their consent at any time and that they would have an opportunity to read the transcription of the interview to clarify their intent, and to add information which may have been omitted during the interview. It was also reinforced at this time that their privacy would be respected by the use of a pseudonym.

Privacy and confidentiality was maximised during phase 1 of this research by maintaining confidentiality of participants, and of the names of residents involved as well as the institution where the research was conducted. If the resident was named during the interview by the participant, the resident's name was changed during transcription of the data. This maximised and protected privacy and confidentiality of the resident's identity. The institution was not identified during the interview to maximise the potential that participants and residents could be recognised by a pattern of data or a familiar story.

Another ethical consideration is that close relationships and trust may develop during the research process (Streubert Speziale & Rinaldi Carpenter, 2007). As the researcher becomes part of the community, she may become a confidant and a friend, although less so when conducting interviews than prolonged observation, as was the case with this research study. Personal stories and private information may be shared and this needs special consideration by the researcher. Decisions may need to be made regarding private information passed on by the participant, but the researcher must respect the privacy and confidentiality of the research forum at all times, while considering the morals and integrity of society at large. Although no sensitive information was shared during the interviews for this research study, an awareness of the potential for this to occur was maintained and each interview conducted with due respect for each ACHCP privacy. Thus personal awareness and professional ethics as well as fully informed consent of the participants, underpinned all data collected during this research.

Safe, secure storage of data once collected is another ethical consideration. The data which was collected for phase 1 of this research was kept in a secure place. Recordings which were made of an interview were transcribed to a computer database which was protected by a password known only to the researcher student. The audio recordings were kept in a locked filing cabinet, the key kept by the research student. The data will be kept in this secure

manner for five years and then deleted as required by National Health and Medical Research Council (NHMRC) guidelines (NHMRC, 2007).

Thus issues related to privacy, confidentiality and consent were maintained during phase 1. Privacy and confidentiality of the identity of residents and participants were assured by changing the names of residents if mentioned during an interview and the use of pseudonyms for participants. Consent from participants was gained at the initial interview and was regularly reaffirmed throughout the research process. As a result, no exploitation or harm occurred to the group involved and respect for privacy and confidentiality was maintained.

Chapter 5

Phase 2: Confirmation of End-of-Life Phases: A Delphi Survey

This chapter provides a detailed description of phase 2 of the research. The purpose of this phase was to gain a consensus of opinion from a panel of experts of two of the themes which were identified from phase 1, which described the transition to the EOL phase. These phases were described as an early phase which commenced around two weeks prior to a later phase, which usually commenced around three days before death. Signs of the early phase were decreased appetite, increased frailty and becoming more withdrawn. Signs of the later phase were skin changes, signs of circulation shut down, breathing changes and increased pain on movement. The participants considered that all of the signs of these two distinct phases should be present for the diagnosis of a later phase of care. The chapter commences with a summary of the research design, and then describes the development of the survey tool and data collection processes. Three rounds were offered to achieve a consensus of all but two statements. The chapter concludes with presentation of the results and a discussion of the ethical considerations specific to this phase.

Design

The Delphi technique was selected because it is used to gather data from participants who share a level of expertise in a specific area of practice (Hsu & Sandford, 2007). As discussed in chapter 2, prior to development of the survey, decisions about panel selection and consensus opinion should be made, as well as the time frame for completion of each round.

Panel Selection

Prior to developing the questions for the Delphi survey for this research, a decision about the criteria for the expert panel was made, the size of the panel and the time frame for completion of each round. As the literature suggests, the panel should have adequate knowledge and a related background to the area of research (Keeney et al., 2001; Bond & Bond, 2006; Hsu &

Sandford, 2007). Their selection should be dependent on their qualifications with respect to the subject matter under investigation. In this regard, the panel should be as homogenous as possible as this relates directly to the quality of the results which may be obtained. The panel should be selected from those people who will use the outcomes and come from professional staff members and their support team (Hsu & Sandford, 2007).

The criterion for selection of the 'expert' panel for phase 2 of this research was that it would be made up of ACHCP currently employed in the aged care setting with a minimum of five years experience in aged care. This criterion was applied to improve the potential that the panel was made up of ACHCP who had the required level of expertise working in this setting. Since the landmark work of Benner (1984) was published, five years' clinical experience is generally equated with expert level practice. The participants' work was to have been providing the care to elderly people either in a full time role or in a part time capacity if part of their role was in management or in clinical supervision. It was considered that AINs would be included in this group with RNs and ENs as much of the daily physical care of residents is done by these nurses with supervision by RNs and ENs. Having computer skills, with access to the Internet and an email address, were other criterion for panel selection. A criterion for selection for subsequent rounds was included in the first round as this group were asked to supply their personal email address to indicate their interest in being part of further rounds, as discussed in Chapter 2.

Panel Size

The initial panel size for this phase of the research was largely dependent upon the voluntary responses obtained from round 1. An invitation to participate in this round was e-mailed to four Australia-wide professional aged care nursing associations. In order to protect the privacy of each association's membership, the student researcher was not provided with direct access to members. The invitation was distributed by the relevant association on behalf of the research student, and responses were anonymous. On completion of the first round,

participants were asked to indicate their interest in participating in further rounds by supplying their email address. This enabled further rounds to be sent directly to them without the need for a third person. The panel size for the second round was therefore determined by: i) the number of participants in round 1 who provided an email address for round 2 and, ii) the number of these participants who met the experience criterion of five years.

Number of Rounds

In a Delphi study, the series of questionnaires are referred to as 'rounds'. The number of rounds is variable and is dependent upon the rate that consensus is achieved with each round. However, Hsu and Sandford (2007) suggest that three rounds are usually adequate to achieve a consensus. In this study, this proved to be the case. All statements, with the exception of two, achieved consensus by the end of round 3. If consensus is not achieved by this stage, then clearly there is disagreement which indicates an area where further research is needed (Hsu & Sandford, 2007).

Time Frame

Another consideration prior to developing the survey was the time frame for completion of each round. The data collection period for round 1 was planned to last four weeks, with the following two rounds lasting two weeks, and a one week period allowed for a possible third round. However, once data collection was commenced, it became apparent that several reminders were needed in each round to improve the response rate. This required the data collection periods to be extended in every round.

Data analysis for each round required simple descriptive statistical analysis. The aim is to calculate the strength of agreement with each statement in the previous round to determine: i) which statements achieved the required consensus level and, ii) the strength of agreement/disagreement of those statements that did not achieve consensus.

Consensus

In a Delphi survey a consensus is achieved through a series of questionnaires which are reviewed and reoffered until an agreement is reached (Keeney et al., 2001; Hsu & Sandford, 2007). As discussed in chapter 3, the literature suggests that a consensus percentage must be decided prior to offering the survey.

It was decided for this research, that a consensus of 75% would be the minimum level of agreement or disagreement for each statement in the Delphi survey. This percentage was considered appropriate as an acceptable and valid level of consensus for a professional opinion in the aged care setting as a speciality area of practice. For this study, the consensus level was set at a relatively high percentage in order to maximise the potential that the statements were fully supported by a significant proportion of the profession represented by the panel. It was considered that having more than five years' experience in the aged care setting would maximise the potential that these participants would have a high level of expertise due to this length of time working in this speciality area.

A Likert scale was used in round 1, with a five-level item system as discussed in Chapter 3. With consideration for the importance of the selection of the terminology, as discussed previously, these were labelled strongly disagree, disagree, unsure, agree and strongly disagree. It was considered that this would enable participants to make a clear decision about their own professional knowledge without feeling they were being pressured to make a choice which did not adequately describe their level of agreement or disagreement with the statement.

In the second round, in order to help panel members to make a clear decision about each statement, the neutral value 'unsure' was removed. As discussed in Chapter 2, when the neutral value is removed it is described as a 'forced choice' and is a strategy often used in Delphi surveys (Sirkin, 2006; Bond & Fox, 2007).

Survey Tool

The survey tool was developed to reflect two of the themes which were identified during phase 1. It reiterated the two distinct EOL phases that were described by participants during the interviews; the first occurring approximately two weeks before death and the second, around two to three days prior to death. These two phases were termed an Early Phase and a Later Phase.

The survey tool was presented in four sections which were titled Biographical Details, General Overview, Signs Indicating an Early Phase and Changes That May Be Seen Later (see Appendix E). The wording of each statement reflected findings about the EOL phases which were identified in the phase 1 analysis. Each statement contained wording and phrases which were repeated to facilitate its understanding with participants, and was carefully constructed to make sure it was not ambiguous. Each was then reviewed and revised a number of times during the development of the survey tool.

The survey opened with an introduction and an invitation to participate in the survey (see Appendix E). This was a way to maximise that potential participants had a clear understanding of what was expected of them and what the survey was about. It also clarified the length of time completion of this survey would take, based on the pilot study, and advised them clearly of the closing date.

Section 1: Biographical Details

The purpose of the first section was to elicit information about the participants and their professional practice. Questions included years of experience in the aged care setting, professional qualifications and highest level of advanced study each participant had completed in the past five years in areas of aged care, palliative care and dementia care; the state or territory in which they were located and their main area of nursing practice. This

information was used to gain a picture of the participants who completed the survey and to identify those participants who met the experience criterion of five years for round 2.

Section 2: General Overview

As noted above, two themes that emerged from phase 1 analysis described two distinct phases which occurred prior to the death of a resident. Section 2 contained general, broad statements about these two phases. These statements were carefully worded to succinctly summarise the findings identified in phase 1 and required participants to indicate their strength of agreement with each. Wording was specific and key words and phrases were repeated to maximise participants understanding. These are underlined below.

There were three statements:

- There are definite indicators that a resident with high level care needs may die soon.
- There is an initial or early phase of change in a resident's condition which commences around two weeks before death.
- There is a second or later phase of change in a resident's condition which commences two to three days before death.

Section 3: Signs Indicating an Early Phase

The third section was specific to the early phase, which was identified in phase 1 as commencing around two weeks before death (Table 4). Statements were made in the survey that required participants to indicate their strength of agreement with each of the signs of this early phase of EOL. These signs were described using the term 'indicators'. As with the previous section wording and phrases were repeated to maximise participants' understanding and these are underlined in the statements below:

- A change associated with the early phase is a recent decreased appetite, where the resident may not be able or willing to eat.

- A change associated with the early phase is that the resident becomes suddenly more frail.
- A change associated with the early phase is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations.

Participants were asked to indicate their level of agreement with each of the early phase indicators. Each statement commenced with the same information and phrases were repeated to reinforce and clarify the common theme. To reinforce that these statements were concerned with the early phase of changes, the words "in the early phase" and "recent" were purposely repeated and the exact wording of each sign repeated. For example, the phase 1 analysis indicated that a sign which may confirm the early phase of change is a decreased appetite. To clarify that participants were fully aware that they were being asked to indicate their strength of agreement with each indicator, the exact wording of each indicator was repeated in the stem statement. These key words and phrases are underlined below.

Please indicate below your strength of agreement with the indicators of a decreased appetite by ticking the relevant box. In the early phase:

- The resident has often started to spit food out
- The resident has recently started to drool
- The resident's swallow has deteriorated recently
- The resident has a recent significant weight loss.

Please indicate below your strength of agreement with the indicators of increased frailty by ticking the relevant box. In the early phase:

- The resident's physical capacity has decreased significantly
- The resident has recently been unable to assist with usual activities and has become weaker.

Please indicate below your strength of agreement with the indicators of becoming more withdrawn by ticking the relevant box. In the early phase:

- Recently the resident does not seem to recognise once familiar people
- The resident has recently developed a faraway or vacant look
- The resident has recently developed limited or no verbal interaction.

Finally, participants were asked to indicate their level of agreement with the statement that presence of all of the indicators identified in this section 3 was necessary to confirm the early phase. Again, key words and phrases were repeated to maximise participants understanding of their meaning:

- To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, all three conditions of recent decreased appetite, sudden increased frailty and recent acute withdrawal must be present.

Section 4: Changes That May Be Seen Later

This section of the survey referred to the later or later phase around two to three days before death (Table 4). As in the previous sections, common words and phrases were repeated to maximise clarity and understanding and to reinforce their meaning. To emphasise the term "later phase" the phrase "a very recent change" was used and this was repeated throughout this section:

- A very recent change in the usual condition of the resident which may be associated with a later phase is a change to the usual skin colour.
- A very recent change in the usual condition of the resident which may be associated with a later phase is poor peripheral circulation.
- A very recent change in the usual condition of the resident which may be associated with a later phase is a change to their usual breathing pattern.

- A very recent change in the usual condition of the resident which may be associated with a later phase is sudden increased pain on movement. This may be a sudden worsening of pain which was present already or a new acute event.

As with the previous section, participants were required to indicate their level of agreement with several indicators of this EOL phase (summarised in Table 4). Each statement commenced with the same wording and phrases were repeated to reinforce and clarify the common theme. To emphasise that these statements were concerned with the changes that may be seen later, the words "in the later phase" and "recently" were repeated. These are underlined below:

Please indicate your strength of agreement with indicators of skin changes by ticking the relevant box. In the later phase:

- The resident's skin has recently marked or discoloured on the side they were lying
- The resident's skin has recently become mottled.

Please indicate your strength of agreement with indicators of circulation shutting down by ticking the relevant box. In the later phase:

- Recently the resident's skin has become a dusky, grey colour
- Recently the resident's extremities, hands, feet, lips or nose are a bluish colour.

Please indicate your strength of agreement with indicators of breathing changes by ticking the relevant box. In the later phase:

- The resident has recently developed apnoea or periods of no breaths which did not occur before this time
- The resident has recently developed dyspnoea or difficulty breathing which did not occur before this time

- The resident has recently developed a moist chest or rattling breathing which did not occur before this time.

The statements above were further clarified with the phrase "which did not occur before this time" as it was identified by the experience of the research student that chronic respiratory problems are often evident in this elderly population.

The final statement in section 4, as with the previous section, asked for participants' level of agreement with the statement that all four conditions should be present for confirmation of this later phase of EOL. Again, phrases and words were repeated to maximise participants understanding and that the meaning was clear:

- To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, all four conditions of: changes to the usual skin colour, poor peripheral circulation, changes to the usual breathing pattern and sudden increased pain on movement must be present.

The terms, phrases and wording of the survey were reviewed and revised and many changes were made to maximise that each concept was clear and the meaning understood from a ACHCPs perspective. One statement which was included in an earlier version of the survey was "bed bound". This term was reviewed as there was concern that it might be misinterpreted. In the final version the term was included as it was considered that it was a colloquial term that was readily understood by participants practising in the clinical setting. When the survey was finalised and the wording of each statement was considered clear, it was piloted with a small sample of experienced ACHCP.

Survey Tool Pilot

The purpose of the pilot study was to gather information about the reliability and validity of the Delphi survey tool, as discussed previously in Chapter 3. Specifically, it was used to test the wording and flow of questions to maximise that they were clear and that the survey was

easy to navigate before the final version was offered to the expert group. The pilot survey was an online survey and was distributed to a small, voluntary group of ACHCP with experience in both research and in the aged care setting.

The pilot survey was sent to six ACHCP, however only four responded. They were asked to trial the survey and answer questions in a final section about navigation of the survey, wording and order of questions. They were also asked to indicate the length of time taken to complete the survey, which ranged from 15 to 30 minutes. This information was used to state clearly the length of time potential participants could expect to take to complete the survey.

At the commencement of the pilot survey it was stated clearly that this was a pilot survey, the purpose being to identify any areas which may not be clear or which have not been considered (Appendix F). It was also stated to the pilot group that their responses would not be taken into account with the final results of the survey. An opportunity was also given this pilot group to add comments throughout the survey as free text comment boxes were added at the end of each statement and at the completion of the survey.

The comments provided by the pilot group indicated that they found the survey easy to navigate. However, only two found the questions easy to understand, while one was unsure, and one did not find them easy to understand. As a result, the wording was reviewed and revised accordingly. The pilot group was also given the opportunity to comment about anything else they thought might be helpful to maximise ease of use and understanding of the survey by the participants in the final survey. The main change identified by them was the need for an 'other' choice in the first section of the survey as they were unable to move past that question unless they chose any of the answers. Other changes which were made in response to the pilot group were grammatical corrections related to spelling and punctuation.

In summary, the pilot group reported that the survey was easy to navigate. In response to comments received wording was reviewed and changes were made. The information provided by the pilot group was for the purpose of fine-tuning the survey and was not taken

into account with the data collected from the survey. This provided excellent feedback and a way to clarify that the final survey tool was valid and reliable when offered to the expert panel.

Data Collection

Recruitment

In round 1 the survey tool was distributed to members of four professional organisations, as discussed previously. For round 1, a weblink to the survey was distributed by email to each organisation's members by a key person in each organisation. In this way potential participants' privacy was protected, and they were anonymous to the student researcher. A final question in this round, asked participants to provide an email address if they wished to volunteer to participate in further rounds (see Appendix E). Therefore, the round 2 initial sample comprised of volunteers who had responded to round 1 and had elected to participate in further rounds. From this group, those with greater than five years' experience were selected for participation in subsequent rounds. This determined the initial round 2 panel size of 20. However, one email address that was provided was incorrect and unable to be used, leaving a panel size of 19.

Round 1 data collection commenced 28th February 2010 and was planned to last for four weeks. Because the initial emails were managed by each organisation directly, a reminder note to any potential panel members was not possible as their contact details were not known. Although an initial closing date was set, it was extended for a further week to allow more time for responses. This resulted in a final panel size of 40 in round 1.

Round 2 participants were emailed directly and reminders were sent directly to non-responders. Data collection for round 2 commenced 26th March 2010 and it was planned to offer this round for two weeks. At the initial cut off date there were only six participants. Therefore, a reminder email was sent to the 13 non-responders, offering a further two weeks

to respond. This resulted in another seven responses. The remainder was sent another reminder email extending the cut-off date for a further week. However, this did not result in any further responses. The final panel size in round 2 was 13.

Round 3, the final round, was again offered to all 19 panel members from the initial round. This round commenced on 11th April 2010 and was offered for two weeks. At the initial cut-off date nine people had responded. A reminder was sent and data collection was extended for another two weeks. The panel size for the final round was 13.

In round 2 and round 3 the Likert scale was modified; the neutral value was removed to require a 'forced choice' response. In round 2 the middle value of "unsure" was removed and a four point Likert scale was used. In round 3, only two values were used and participants were asked to agree or disagree only, with each statement. In rounds 2 and 3 participants were provided with the percentage values that indicated the strength of agreement with each statement in the previous round and asked if they would be willing to conform to the consensus view.

Data Analysis

Data were analysed after the results were entered into an Excel database created by the computer generated survey tool (see Appendices G, H and I). The total of the percentages for agree and strongly agree were added together as were the totals for strongly disagree and disagree. This provided a total percentage which if equal to or greater than 75% was considered to be a consensus for that statement. If a consensus was not achieved for a statement it was re-offered in subsequent rounds.

Results

Of the 40 participants who started the first round of the survey, 29 (70%) completed it. Of these 25 participants indicated their interest to participate in further rounds (see Appendix G). In order to obtain the required 'expert' panel, a further exclusion criterion was added to the

selection for the final two rounds, which was that each respondent had five years' or more experience in the aged care setting. Twenty participants met this criterion, of whom 19 provided a valid email address. Of the 19 panel members who were sent the survey tool in round 2, there were 13 responses (68%). The round 3 survey was also sent to the same19 panel members and there were 13 responses (68%).

Demographics

The participants who completed the first round were members of Australia-wide professional aged care nursing associations. Although 40 participants started the survey, 29 completed it. Some members opted to partially answer questions related to biographical details (Table 5.1). Of the 40 who completed this initial section of round 1, six had less than five years' experience in this setting while 14 had worked in aged care between five and ten years and 20 for more than ten years. All levels of ACHCP were represented which were one AIN, four ENs and 35 RNs. Of the original 40 participants, four were employed in a public facility, six in a not-for-profit facility and 30 (75%) in a private facility. Ten participants were from aged care facilities in New South Wales, nine from Queensland, seven from Western Australia, one from Victoria and 13 from South Australia. The main areas of practice were clinical and management. Seventeen participants (42%) indicated their main focus was in the clinical area while 16 participants indicated their primary work was management. Of the remainder, two worked in the administrative area, four in education and one in research.

The participants were asked to indicate the highest level of advanced study completed over the past five years in the speciality areas of dementia care, aged care and palliative care. In aged care specific training, ten had none, 11 had completed a short course, three a graduate certificate in aged care and one a graduate diploma. Fifteen indicated they had other qualifications which included management, education and aged care assessment. Twelve had no dementia specific training while 21 (52%) had completed a short course in dementia care, five a certificate in dementia care and two a graduate diploma. In the area of palliative care,

11 had no specific training, 20 (50%) had completed a short course, seven a certificate in palliative care and two a graduate diploma.

Table 5.1 Demographics of participants completing the first round survey.

Years of experience	**< 2**	**> 2 to < 5**	**> 5 to < 10**	**> 10**		
	2	4	14	20		
Professional qualification	**AIN**	**EN**	**EEN**	**RN**		
	1	3	1	35		
Highest level of advanced study in	**None**	**Short Course**	**Certificate**	**Grad Dip**	**Other**	
Aged Care	10	11	3	1	15	
Dementia Care	9	21	5	2	3	
Palliative care	8	20	7	2	3	
Employment sector	**Public**	**Private**	**Not for Profit**			
	4	30	6			
State employed	**ACT/NT/ Tas**	**NSW**	**QLD**	**SA**	**VIC**	**WA**
	0	10	9	13	1	7
Main area of practice	**Admin**	**Clinical**	**Education**	**Manage -ment**	**Research**	
	2	17	4	16	1	

Consensus levels from each statement

A consensus for each statement was considered to have been achieved when the total for strongly disagree/disagree or strongly agree/agree was 75% or more.

Round 1

Each statement and the consensus level which was achieved in round 1 are presented below (Appendix G). In section 2, General Overview, participants agreed with the statements that there are definite indicators (92%) that a resident may die soon and that there is a later phase

(79%) around two weeks before death (Table 5.2). Consequently these questions were not offered in subsequent rounds. A consensus was not reached when asked about an early phase and therefore this statement was re-offered in round 2.

Table 5.2 Consensus statements, Round 1, General Overview.

General Overview	**n**	Strongly Agree	Agree	Not sure	Disagree	Strongly disagree
There are definite indicators that a resident with high level care needs may die soon.	38	31.6% (12)	60.5% (23)	0	7.9% (3)	0
Consensus agreement totals	35	92.1%				
There is an initial or early phase of change in a resident's condition which commences around two weeks before death.	38	5.3% (2)	47.4% (18)	26.3% (10)	21.1% (8)	0
Consensus agreement totals	0					
There is a second or later phase of change in a resident's condition which commences two to three days before death.		13.2% (5)	65.8% (25)	15.8% (6)	5.3% (2)	0
Consensus agreement totals	30	79%				

In section 3, Signs Indicating an Early Change, a consensus indicated that participants agreed that a decreased appetite was a good sign of the early phase. When asked what the best indicators of this early phase were, participants agreed that deterioration in swallowing and significant weight loss were both good indicators of a decreased appetite (Table 5.3). However no consensus was reached for spitting out food and drooling as indicators and these statements were re-offered in round 2. Participants agreed that increased frailty is another good sign of the early phase. They also agreed that decreased physical capacity and becoming weaker were good indicators of increasing frailty (Table 5.3). These statements were not re-offered in subsequent rounds as a consensus had been achieved.

Participants indicated uncertainty that becoming more withdrawn was a sign of the early phase and there was no agreement regarding the three indicators of this sign so these

statements were re-offered in round 2. The final statement in this section asked participants to indicate their level of agreement/disagreement with the statement suggesting that all three conditions be present to indicate this early phase. Opinion was fairly evenly split between agree (37%), disagree (50%) and unsure (13%), so this statement was re-offered in round 2.

Table 5.3 Consensus statements, Round 1, Signs Indicating an Early Phase.

Signs Indicating an Early Change:	**n**	Strongly Agree	Agree	Not sure	Disagree	Strongly disagree
A change associated with the early phase is a recent decreased appetite, where the resident may not be able or willing to eat.	32	21.9% (7)	65.6% (21)	6.3% (2)	6.3% (2)	0
Consensus agreement totals	28	87.5%				
Indicators of a decreased appetite in the early phase are: • The resident has recently started to spit food out	30	13.4% (4)	46.7% (14)	16.7% (7)	23.3% (7)	0
Consensus agreement totals	0					
• The resident has recently started to drool	30	0	40.0% (12)	26.7% (8)	33.3% (10)	0
Consensus agreement totals	0					
• The resident's swallow has deteriorated recently	31	6.5% (2)	80.6% (25)	3.2% (1)	9.7% (3)	0
Consensus agreement totals	27	87.1%				
• The resident has a recent significant weight loss	30	13.3% (4)	66.7% (20)	6.7% (2)	13.3% (4)	0
Consensus agreement totals	24	80.0%				
A change associated with the early phase is the resident becomes suddenly more frail.	32	9.4% (3)	68.8% (22)	6.3% (2)	15.6% (5)	0
Consensus agreement totals	25	78.2%				
Indicators of increased frailty in the early phase are: • The resident's physical capacity has decreased significantly	31	19.4% (6)	67.7% (21)	3.2% (1)	9.7% (3)	0
Consensus agreement totals	27	87.1%				

• The resident has recently been unable to assist with usual activities and has become weaker	29	17.2% (5)	72.4% (21)	3.4% (1)	6.9% (2)	0
Consensus agreement totals	26	89.6%				
A change associated with the early phase is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations	32	9.4% (3)	46.9% (15)	21.9% (7)	21.9% (7)	0
Consensus agreement totals	0					
Indicators of becoming withdrawn in the early phase are: • Recently the resident does not recognise once familiar people	30	0	20.0% (6)	16.7% (5)	53.3% (16)	10.0% (3)
Consensus agreement totals	0					
• The resident has recently developed a faraway or vacant look	30	6.7% (2)	43.3% (13)	20.0% (6)	26.7% (8)	3.3% (1)
Consensus agreement totals	0					
• The resident has recently developed limited or no verbal interaction	32	0	53.1% (17)	18.8% (6)	28.1% (9)	0
Consensus agreement totals	0					
To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, all three conditions of recent decreased appetite, sudden increased frailty and recent acute withdrawal must be present.	32	0	37.5% (12)	12.5% (4)	46.9% (15)	3.1% (1)
Consensus agreement totals	0					

In the next section, section 4, Changes That May Be Seen Later, participants agreed that skin changes were a good sign of the later phase (Table 5.4). A consensus was also achieved with indicators of skin changes being marking or discolouration and mottling. The statements regarding skin changes and their indicators were not re-offered in subsequent rounds. A consensus was achieved with participants agreeing with poor peripheral circulation being an

excellent sign of a later phase. The indicators of poor peripheral circulation dusky grey colour to the skin and bluish extremities also achieving a consensus (Table 5.4). These statements were not re-offered in the following rounds.

A consensus for the statements regarding changes to the usual breathing pattern being a good sign of a change in the later phase, with the indicators of changes to breathing pattern being apnoea, dyspnoea and moist breathing (Table 5.4). These statements were therefore not re-offered. Participants were also asked to confirm that increasing pain on movement was a good sign of this later phase. A consensus of this statement was achieved in this round with 75% of participants agreeing with this statement which was not reoffered in consequent rounds (Table 5.4). As with the previous section, the final statement asked participants to agree/disagree that all four conditions be present to confirm this later phase. A consensus was not achieved with 48% disagreeing, 48% in agreement and 4% unsure. This statement was therefore re-offered in round 2.

Table 5.4 Consensus statements, Round 1, Changes That May Be Seen Later.

Changes That May Be Seen Later:	**n**	Strongly Agree	Agree	Not sure	Disagree	Strongly disagree
A very recent change in the usual condition of the resident which may be associated with a later phase is a change to the usual skin colour.	29	10.3% (3)	75.9% (22)	10.3% (3)	3.4% (1)	0
Consensus agreement totals	25	82.6%				
Indicators of skin changes in the later phase: • The resident's skin has recently marked or discoloured on the side they were lying	25	16.0% (4)	76.0% (19)	0	4.0% (1)	4.0% (1)
Consensus agreement totals	23	92.0%				
• The resident's skin has recently become mottled	29	13.8% (4)	72.4% (21)	10.3% (3)	0	3.4% (1)
Consensus agreement totals	25	86.2%				
A very recent change in the usual condition of the resident which may be						

associated with a later phase is poor peripheral circulation.	29	17.2% (5)	82.8% (24)	0	0	0
Consensus agreement totals	29	100%				
Indicators of poor peripheral circulation in the later phase: • Recently the resident's skin has become a dusky grey colour	27	7.4% (2)	81.5% (22)	3.7% (1)	7.4% (2)	0
Consensus agreement totals	27	88.9%				
• Recently the resident's extremities, hands, feet, ears, lips or nose are a bluish colour	29	10.3% (3)	86.2% (25)	3.4% (1)	0	0
Consensus agreement totals	28	96.5%				
A very recent change to the usual condition of the resident which may be associated with a later phase is a change to their usual breathing pattern.	29	24.1% (7)	72.4% (21)	0	3.4% (1)	0
Consensus agreement totals	28	96.5%				
Indicators of breathing changes in the later phase: • The resident has recently developed apnoea or periods of no breaths which did not occur before this time	28	25.0% (7)	71.4% (20)	0	3.6% (1)	0
Consensus agreement totals	27	96.4%				
• The resident has recently developed dyspnoea or difficulty breathing which did not occur before this time	28	10.7% (3)	71.4% (20)	14.3% (4)	3.6% (1)	0
Consensus agreement totals	23	82.1%				
• The resident has recently developed a moist chest or rattling breathing which did not occur before this time.	29	17.2% (5)	79.3% (23)	0	3.4% (1)	0
Consensus agreement totals	28	96.5%				
A very recent change to the usual condition of the resident which may be associated with a later phase is sudden increased pain on movement. This may be a sudden worsening of pain which was present already or a new acute event.	29	10.3% (3)	65.5% (19)	10.3% (3)	13.8% (4)	0
Consensus agreement totals	21	75.8%				

To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, all four conditions of: changes to the usual skin colour, poor peripheral circulation, changes to the usual breathing pattern and sudden increased pain on movement must be present.	29	6.9% (2)	41.4% (12)	3.4% (1)	48.3% (14)	0
Consensus agreement totals	0					

In summary, in round 1, 19 statements of the 28 achieved consensus.

The remaining nine statements were re-offered into round 2.

Round 2

Round 2 was offered to the 19 participants who indicated their interest in being part of further rounds and who met the criterion of five or more years aged care experience, as discussed previously (Table 5.5). Six of the 19 participants had between five and ten years' experience in the aged care setting while the remaining 13 had more than ten years experience. One participant was an AIN and 18 were RNs. Eight of the participants worked in the clinical setting, seven in management, two in education, one in research and one in administration. All of the participants had done short courses in aged care, dementia care or palliative care, while two had a Certificate in Aged Care and five a Certificate in Palliative Care.

This round was presented in a single section (see Appendix J). The nine statements which did not achieve a consensus in round 1 followed each other in a logical order, worded clearly to make sure the flow was logical and clear. Prior to each statement it was clearly stated what the percent of the majority view was from round 1, what the expected percentage for a consensus was, and what the responses were for each choice. Participants were asked if they would be willing to conform to the majority view. The middle value of "unsure" was removed as the aim in this round was to have participants make a clear decision by agreeing

or disagreeing with each statement. Each statement and the consensus level which was achieved in round 2 are presented below.

Table 5.5 Demographics of participants completing round 2 and round 3.

Years of experience	**> 5 to < 10**	**> 10**				
	6	13				
Professional qualification	**AIN**	**RN**				
	1	18				
Highest level of advanced study in	**None**	**Short Course**	**Certificate**	**Grad Dip**		
Aged Care	3	1	2	1		
Dementia Care	3	10		1		
Palliative care	3	9	5			
State employed	**ACT/NT/ Tas**	**NSW**	**QLD**	**SA**	**VIC**	**WA**
	0	4	5	7	0	3
Main area of practice	**Admin**	**Clinical**	**Education**	**Manage-ment**	**Research**	
	1	8	2	7	1	

In round 1, participants agreed that indicators of a decreased appetite, as a sign of the early phase of change, were a reduced swallow and significant weight loss. However there was no consensus in round 1 of spitting out food and drooling as other indicators of this sign of a change in the early phase. These statements were therefore re-offered in round 2. A consensus was achieved in this round with spitting out food as an indicator of a decreased appetite (Table 5.6). However no consensus was achieved with drooling as another indicator of this sign. This statement was therefore re-offered in round 3. The participants in this round agreed with the statement regarding withdrawal as a sign of the early phase of change (Table 5.6).

Participants disagreed that not recognising once familiar people was an indicator of withdrawal as a sign of the early phase of change (Table 5.6). They agreed that the resident developed a vacant or faraway look and had limited or no verbal interaction as other indicators of this phase of change (Table 5.6). These statements were not re-offered in the next round. The next statement was broken into three parts to enable participants to indicate which conditions must be present to confirm this early phase of change. Participants agreed that recent decreased appetite and sudden increased frailty confirmed the early phase of change (Table 5.6). No consensus was achieved with recent acute withdrawal with 46% disagreeing and 54% in agreement with this statement which was re-offered in round 3.

As with the previous statement, the final statement was also broken into four separate conditions to enable participants to indicate their agreement or disagreement with conditions which must be present to confirm this later phase of change. Participants agreed that changes to skin colour, poor peripheral circulation and changes to usual breathing pattern confirmed this later phase of change (Table 5.6). However, no consensus was reached with sudden increased pain on movement as the final sign confirming this phase, with five (42%) disagreeing and eight (58%) agreeing with this statement. This final statement was re-offered into round 3.

Table 5.6 Consensus Statements, Round 2.

Statement	**n**	**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**
There is an initial or early phase of change in a resident's condition which commences around two weeks before death.	13	0	92.3% (12)	7.7% (1)	0
Consensus agreement totals	12	92.3%			
Indicators of a decreased appetite are: • The resident has recently started to spit food out	13	0	84.6% (11)	15.4% (2)	0
Consensus agreement totals	11	84.6%			

• The resident has recently started to drool	13	0	46.2% (6)	53.8% (7)	0
Consensus agreement totals	0				
A change associated with the early phase is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations.	13	7.7% (1)	84.6% (11)	7.7% (1)	0
Consensus agreement totals	12	92.3%			
Indicators of becoming more withdrawn in the early phase are: • Recently the resident does not seem to recognise once familiar people	13	0	15.4% (2)	76.9% (10)	7.7% (1)
Consensus agreement totals	11			84.6%	
• The resident has recently developed a faraway or vacant look	13	0	100.0% (13)	0	0
Consensus agreement totals	13	100.0%			
• The resident has recently developed limited or no verbal interaction	0	0	92.3% (12)	7.7% (1)	0
Consensus agreement totals	13	92.3%			
To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, all three conditions of: • recent decreased appetite	13	23.1% (3)	61.5% (8)	15.4% (2)	0
Consensus agreement totals	11	84.6%			
• sudden increased frailty	12	16.7% (2)	58.3% (7)	25.0% (3)	0
Consensus agreement totals	9	75.0%			
• recent acute withdrawal must be present.	13	0	53.8% (7)	46.2% (6)	0
Consensus agreement totals	0				
To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, all four conditions of: • changes to the usual skin colour	13	7.7% (1)	76.9% (10)	15.4% (2)	0
Consensus agreement totals	11	84.6%			

• poor peripheral circulation	12	16.7% (2)	75.0% (9)	8.3% (1)	0
Consensus agreement totals	11	91.7%			
• changes to the usual breathing pattern	13	23.1% (3)	76.9% (10)	0	0
Consensus agreement totals	13	100.0%			
• sudden increased pain on movement must be present.	12	0	58.3% (7)	41.7% (5)	0
Consensus agreement totals	0				

As a result, of the nine statements offered in round 2, six achieved a consensus and were not re-offered. The three statements that did not achieve a consensus were re-offered in a third and final round.

Round 3

In round 3 the remaining three statements from round 2 which did not achieve a consensus, were reoffered to the panel of experts (Appendix K). These statements were worded identically to the previous round to maximise clarity of understanding. As in the previous round, prior to each statement it was clearly stated what the percent of the majority view was from round 2, what the expected percentage for a consensus was, and what the responses were for each choice, and participants were asked if they would be willing to conform to the majority view. In this round, only two values were used and participants were asked to agree or disagree with each statement. A consensus was achieved and participants disagreed that drooling was an indicator of a decreased appetite in the early phase (Table 5.7). However, no consensus was reached with the final two statements regarding indicators which confirm both the early phase and the later phase of change.

Table 5.7 Consensus Statements, Round 3.

Statement	**n**	Agree	Disagree
In the early phase an indicator of a decreased appetite is: • The resident has recently started to drool	13	23.1% (3)	76.9% (10)
Consensus agreement totals	10	76.9%	
An indicator which confirms that a resident has entered an EARLY PHASE of change associated with the end-of-life phase is Recent Acute Withdrawal.	13	61.5% (8)	38.5% (5)
Consensus agreement totals	0		
An indicator which confirms that a resident has entered an LATER PHASE of change associated with the end-of-life phase is Sudden Increased Pain on Movement.	13	61.5% (8)	38.5% (5)
Consensus agreement totals	0		

Summary of Phase 2 Results

The outcome of phase 2 of this research project is summarised in Table 5.8. Panel participants indicated that there are two distinct phases which signify to them that a resident being cared for in a high level aged care facility may die soon. There is a early phase around two weeks before a later phase which occurs two to three days before death.

The signs which indicate the presence of the early phase are decreased appetite, increased frailty and becoming withdrawn (Table 5.8). Indicators of these signs were confirmed as being spitting out food, a poor swallow and profound weight loss indicating a decreased appetite, more bed bound and increased weakness indicating increased frailty and a faraway or vacant look combined with limited or no verbal interaction to indicate becoming withdrawn. All of these signs and indicators needed to be present to confirm the early phase.

The signs which indicate the presence of the later phase were confirmed as skin changes, circulation shut down and breathing changes. The indicators of these signs were increased

marking and mottled skin to indicate skin changes; dusky skin colour and bluish feet, hands, ears and lips as indicators of circulation shut down; apnoea, dyspnoea and moist chest to indicate breathing changes. The participants agreed that all these signs and helpful indicators should be present to confirm the later phase of care (Table 5.8).

Table 5.8 Final outcome of consensus for the phases, signs and indicators of the end-of-life stage for residents being cared for in high level aged care facilities.

Phase	Sign	Indicators
Early	Decreased appetite	spits food out
2 weeks prior to later phase		poor swallow
		profound weight loss
	Increased frailty	more bed bound
		increased weakness
	Withdrawn	vacant or faraway look
		limited or no verbal interaction
Later	Skin changes	increased marking
2-3 days prior to death		mottled skin
	Circulation shut down	dusky colour to skin
		bluish feet, hands, ears, lips
	Breathing changes	Apnoea
		dyspnoea
		moist chest

Phase 2 Ethical Considerations

Respect for privacy and anonymity were important considerations prior to offering the survey to the round 1 panel. In the subsequent rounds, confidentiality was the primary concern. Anonymity of the participants was maintained by use of the Internet via a weblink in the first round. Initially, this was managed by a third person who forwarded an invitation to Australia-wide peak bodies in aged care. These were Aged and Community Services Australia (ACSA), Aged Care Association of Australia (ACSA), Nurses in Management Aged Care

(NIMAC) and LeeCarePlus. The members of these organisations were invited to be part of the first round of the survey. On completion of this round, participants were asked if they were interested in being part of further rounds in the survey by answering yes or no to a final question. If their answer was no, then no further contact was made with them. If they answered yes, they were asked to provide their email address but no other details. This was used to forward further survey rounds directly to them and provided a way of tracking who had responded to each round, according to their email address.

Although none of the round 2 participants were required to provide any other personal identifying details, potentially many of them could have been identified by their email addresses and basic demographic details they provided. For this group, confidentiality was ethically important. Therefore, only the research student and principal supervisor had access to these email addresses and, in all research outputs, including this thesis, only aggregated data is provided. The email database was stored on a secure server, which was password protected. No other information was known about the participants, thus their anonymity (round 1) and confidentiality (round 2 onwards) were protected. From round 2 onwards, reminder notices were sent to panel members who had not responded, via their personal email address. Data collection closing dates were extended as necessary.

Consent to participate in the survey was presumed by the completion and submission, and their round 1 indication of interest to participate in future rounds by supplying an email address. That their implied consent was indicated by their submission of the survey was explained to them in writing in both their initial covering letter/email and within the initial welcome/instructions at the commencement of each survey round.

Chapter 6

DISCUSSION

Analysis of the data in phase 1 identified two distinct EOL phases - an early phase and a later phase. These phases were described in detail in Chapter 4. The phases, and the relevant signs and indicators associated with them, were confirmed by consensus in phase 2, using Delphi methodology (Chapter 5). The findings of this research study have confirmed existing knowledge for nursing practice in the aged care setting. Specifically, it has confirmed an early phase of change associated with the early signs of EOL.

A study conducted by Porock and Oliver (2007) aimed to explore how staff in long-term care facilities recognised that a resident was dying. The researchers interviewed all levels of staff, "both licensed and un-licensed" in long-term care facilities in the United States. The findings identified that staff were able to recognise certain cues which alerted them to the potential transition of the resident to the EOL phase. Participants in this study identified that this process was often preceded by an event such as a fall or a "significant family event" which resulted in the resident questioning any further treatments and was a prelude to an awareness by the resident that they may be approaching the final stages of their life and this was often verbalised by them to the staff (Porock & Oliver, 2007). These initial cues were followed by "the look about them" which indicated that the resident would certainly die soon.

In the setting of residential aged care, the findings of this research confirm the recognition of the EOL phase, with the identification of an early phase around two weeks before death. Furthermore, the findings of this research have led to a refinement of the signs associated with the later phase of care, two to three days before death. The traditional signs used in palliative care settings, which indicate the commencement of the later phase were discussed in Chapter 2, and were outlined in Table 2.1. These have been refined in response to the findings from this study and existing research (Porock & Oliver, 2007). Modification of the signs

associated with the later EOL phase has resulted in a set of signs and indicators that are specific to elderly residents in long-term aged care settings. Also associated with transition to the EOL phase was a general change in the way residents appeared. This has confirmed existing research in the aged care setting and affirms participants' description of the way residents "get a certain look about them". This "look" alerted ACHCP to the possibility that a reassessment of the resident was needed.

Participants interviewed in phase 1 of this study described how they were able to look at a particular resident and recognise that something was different about them. They indicated that this enhanced observational ability was due to the intimate relationship which develops over time with a resident as well as skills and understanding gained from their own experience in the aged care setting. Informal knowledge of this nature is termed tacit knowledge, which is described in the literature as the hallmark in developing expertise as an advanced skill of nursing practice (Welsh & Lyons, 2001; Herbig, Büssing & Ewert, 2001; Lake, Moss & Duke, 2009). Welsh and Lyons (2001) identified that traditional approaches to clinical assessments and decision making were challenged when ACHCP used intuition and tacit knowledge when assessing the needs of people with complex health problems. Schön (1983) discussed the notion that professional decision-making is enhanced when a person is able to move from the technical knowledge acquired through formal learning to the ability to reflect on an action, as a way of developing their professional knowledge.

Tacit knowledge then can be described as the skills and knowledge informed by reflection both during and after an event as a way of developing advanced skills which ACHCP, with many years experience, use to identify changes in their patient's condition. This is an important aspect of nursing practice especially when caring for elderly people at the end of their life when signs of this phase of care may be difficult to determine. Analysis of the data from phase 1 identified that participants were able to reflect on their professional experiences and practice

as means to identify the signs and indicators which signify to them that an elderly resident with high level care needs has entered the EOL phase of care.

The Guidelines for a Palliative Approach in Residential Aged Care which were introduced in 2004 (NPCP, 2004), aimed to provide ACHCP with a comprehensive set of guidelines and tools in which the most appropriate care could be given to RACF residents. These guidelines have been available as a resource for several years. However, the signs of the later phase used to date, in many care settings, (Table 2.1) are the only set of signs which are present within the guidelines for ACHCP which identify the EOL phase of care. As discussed previously in Chapter 2, ACHCP find these signs limiting in the RACF setting.

Based on the findings of this research and those from existing research conducted by Porock and Oliver (2007), it is possible to identify commencement of the EOL phase much earlier; around two weeks before death. Confirmation of the early phase may assist ACHCP in making the most appropriate clinical decision regarding the care of a resident at the early commencement of the EOL phase (Jones & Johnstone, 2004; Matzo, 2004; Goodridge et al., 2005; Hockley et al., 2005; Porock, et al., 2005; Partington, 2006; Carlson, 2007; Porock & Oliver, 2007). The decision however relies on confident and competent identification of the early signs and indicators of the early phase by ACHCP who are well informed and educated and understand these changes. However, although RNs may be aware of the signs and indicators associated with EOL, in the RACF setting it is usually the AIN who has most contact with the resident. Therefore it is important that they too are able to not only recognise the signs when they are present but also to interpret their meaning.

The AIN described her role as being the 'eyes and ears' for the RN. This description is especially relevant as the RNs role is that of supervision and direction of other staff: ENs, AINs, and care staff. An RN may not be in a position to assess every resident in their care each shift due to other responsibilities, which include administration of medication, attending wound care, arranging medical reviews and appointments for residents. Therefore, it is

frequently the case that RNs do indeed rely on others to be their 'eyes and ears', trusting junior colleagues to alert them to any unusual signs. It is important, then, that all nursing staff are appropriately educated and able to monitor and report the changing health status of residents. Therefore, in the context of EOL care in the RACF setting, the findings of this research and resultant confirmation of existing research, have implications for education and training of nursing staff.

While ENs have undertaken 12 months educational preparation in order for them to be employed as ENs [Australian Nursing Federation (ANF), 2005; Department of Education and Training (DET), 2001], AINs may have either a Certificate 3 in aged care or no formal qualifications. Often they have received only in-house training from the facility in which they are employed (RCNA, 2004; DET, 2010]. There is no specific educational component which is part of the training undertaken by ENs or the Certificate 3 by AINs which is specific to EOL care. Abbey et al. (2006) considered that RACFs are the hospices of the future, therefore ACHCP should have the knowledge and skills which would enable them to deliver the most appropriate EOL care.

The literature review revealed that many ACHCP are reluctant to seek further education and this is considered the main barrier to providing the most appropriate EOL care (Kafetz, 2002; NPCP, 2004; 2006; Hockley et al., 2005; Porock et al., 2005; Abbey et al., 2006). Identification of the signs of this phase is limited by the ability of ACHCP to recognise them. Gambles et al. (2006) considered that recognition of the signs of a later phase would result in the implementation of appropriate EOL care. As was discussed previously, in RACFs the aim of all care is to enable each resident to live the rest of their life without pain and suffering and to provide a supportive environment for them as they enter the EOL phase of care. Using the signs and indicators of the early and the later phase of care may provide ACHCP with the necessary cues which would alert them to the commencement of the EOL phase. In particular, because the signs of this phase are often so discrete, the commencement of the

EOL phase identified at an earlier time, two weeks before the signs of the later phase would provide ACHCP with the opportunity to reassess the resident and initiate appropriate interventions based on this information.

The Early Phase of EOL

The findings from this research have confirmed existing knowledge in an area of nursing concerning the early phase described previously (Chapters 4 & 5). It has specifically confirmed an early phase of care which occurs around two weeks before death. The signs and indicators of this early phase may also be present in other care settings such as hospital, hospice or the home, but may not be recognised as occurring at an earlier time.

A review of the literature provided a summary of the traditional signs commonly identified in many care settings as being associated with of the later phase (Table 2.1) (Ellershaw, et al, 2001; Hallenbeck, 2003; Ellershaw & Ward, 2003; NPCP, 2004; Watson, et al., 2009). Importantly, this research study has identified that only three of the previously recognised signs are relevant to older residents. However, the findings confirmed that in the RACF setting these occur much earlier in a early phase, at around two weeks before death. They are minimal or no oral intake, identified in this research as decreased appetite; profound weakness eventually becoming bed bound which was indentified as increased frailty; and drowsiness, which was described in this study as becoming more withdrawn. These signs are commonly used to signify a later phase and are used in other care settings. In this research thesis these were identified as signs that a person has entered the early or early phase.

The Later Phase of EOL

Signs of the commencement of the later phase have been well documented (Ellershaw, 2001, Hallenback, 2003; NPCP, 2006; Porock et al., 2005; Porock & Oliver, 2007). As discussed previously in Chapter 2 (Table 2.1), these are the only signs which are currently available for ACHCP which may alert them to the possibility that a resident may have entered the EOL

phase of care. Findings from this research study have confirmed the presence of three of them as signs of the commencement of the later phase of EOL. These are breathing changes, recognised by dyspnoea, apnoea and retained secretions; skin changes such as mottling and increased marking; and cool extremities referred to as circulation shut down. Participants indicated that these signs usually occur two to three days before death and are usually preceded by the signs of the early phase.

Although analysis of phase 1 data suggests that increasing pain is a sign of the later phase, a consensus was not achieved in phase 2 of this research study. That is, increasing pain may not always be a sign of the EOL phase in the RACF setting. In phase 2, 61.5% of participants agreed that increasing pain may be present in the terminal phase. As 75%, or more, was considered a consensus for statements in this phase, this may be an area where further research could provide a clearer picture of the presence of increasing pain as a sign of the later phase of EOL.

The early confirmation of transition to the EOL phase of care, using the signs and indicators of the early phase confirmed in this research study, would enable appropriate care to commence at an earlier time than is currently the case. Reassessment of the management of the resident, based on the early identification of the new early phase, would enable commencement of more relevant EOL care by ACHCP, medical practitioners and family members.

Chapter 7

CONCLUSIONS AND RECOMMENDATIONS

The purpose of this research study was to identify the perceptions of ACHCP working in RACFs of the changes that indicate to them a resident had entered the EOL phase. Using a qualitative approach in phase 1, ACHCP were interviewed using semi-structured interviews. The intention was to provide a detailed description of ACHCP shared ideas, beliefs and knowledge to illustrate how they interpret signs and symptoms related to the EOL phase in RACFs. Key findings from phase 1 were confirmed in phase 2.

Information on phases arising from this research is specific to elderly residents with multiple chronic health problems who are cared for in high level RACFs. These residents experience a slow deterioration in physical and mental condition which, as identified in the literature review, makes identification of the EOL phase of care difficult for ACHCP (Kafetz, 2002; Ellershaw & Ward, 2003; Froggatt, et al., 2006; Abbey, et al., 2006).

The findings of this research study have confirmed existing knowledge, that is, the presence of two distinct phases which identify the transition to the EOL phase of elderly residents cared for in high level RACFs (Porock & Oliver, 2007). The phases, in this research, have been termed an early phase which commences around two weeks before a later phase, occurring around three days before death. Signs and indicators of both phases were identified and described, which confirm the EOL phase of care. The findings suggest that all of the signs of both phases should be present to identify the resident's transition to the EOL phase, and that the two phases are sequential.

The signs associated with the early phase were decreased appetite, increasing frailty and becoming more withdrawn. The signs associated with the later phase were changes to the skin, breathing changes and changes to the circulation. The findings of this research confirm the presence of three of the traditional signs of the later phase (Table 2.1) as also being

present in this group. However, these signs may already be present as part of a general deterioration in the elderly and, as a result, are more significant to this group. Analysis of the data indicates that incontinence (which is a sign associated traditionally with the EOL phase) is not a new condition but may have been present for some time. Similarly, the traditional signs of restlessness or agitation and increasing pain may not present in the EOL phase in elderly residents. This is an area in which further research may provide a clearer picture as to the presence of these signs of the EOL phase in this group.

Whilst this knowledge has been known by ACHCP by way of informal or tacit knowledge, the findings of this research have identified and confirmed this informal knowledge and transformed it to formal knowledge, thereby enabling access to it by the nursing profession and the community. Using the findings of this research, informed by existing knowledge, with education and the development of an appropriate assessment tool to identify the EOL phase of care for elderly residents being cared for in RACFs, it is likely that ACHCP will be able to provide more timely and appropriate care at the EOL for elderly people in their care.

The knowledge, confirmed in this research study, could guide the development of a tool which clearly defines the early and later phases and the signs and indicators of them, in order that the EOL phase of care may be verified. The advantage to ACHCP of this clarification is to enhance their confidence in determining that the EOL phase of care has commenced thereby enabling a timely reassessment of medications and care specific to the EOL stage. In this way ACHCP can be more confident that their focus is on the care of the dying person.

The following discussion of the implications of the findings for nursing practice includes the limitations of the study and recommendations for further research in this area of nursing practice.

Implications for Nursing Practice

The implications of the findings from this research for nursing practice are related primarily to the confirmation of the early phase. Of significance for nursing practice in the aged care setting is the clarification and confirmation that this research provides concerning the signs and indicators that are specifically relevant to older people transitioning to the EOL phase following a long-term deterioration of physical and mental capacity.

The implications for nursing practice are that there is a more specific set of signs and indicators than may have been previously understood, might determine the EOL phase of care for RACF residents. It is important to disseminate this knowledge. Through conference presentations, publication, education and further research, the information will be brought to the attention and awareness of ACHCP. In this way, the information can be used to help provide the most appropriate care of residents at the EOL.

Summary

The findings of this research study provide a useful framework for the assessment of the transition to EOL that will support the delivery of the most appropriate care for high care category residents in RACFs at the end of their lives. As discussed previously (Chapter 2), many elderly residents have multiple chronic health conditions which make identification of the EOL phase of care difficult for ACHCP. However, through application of the findings from this research study the early detection of this phase would enable prompt and appropriate nursing care to be commenced that might facilitate a peaceful and symptom free death for the resident. As discussed previously, people with a life-limiting illness deserve access to high quality care delivered by educated and competent staff according to evidence based best practice standards, in a place identified by the person as home (PCA, 2003; NPCP, 2004; PCA, 2005; NPCP, 2006). So, it is important that ACHCP are competent in the delivery of EOL care to residents in their home - the RACF - and to be able to identify the

signs when this stage is reached. Using the findings of this research, which confirms signs and indicators of two distinct phases, an early phase and a later phase, would alert ACHCP to the need to reassess individual residents to confirm their transition to the EOL phase, with a view to implementing the most appropriate care for this final phase of life.

Limitations of the Study

Limitations to this study are primarily the relative inexperience of the research student and the relatively small panel size of the phase 2 Delphi survey.

The inexperience of the research student had an impact on the interview data collected during phase 1. As a reflexive journal was kept by the research student, it was evident when reviewing the journal that the more interviews which were conducted, the more responsive both the research student and the participants became. This was reflected in the participant being more relaxed and affected the quality of the data as each interview conducted brought a more relaxed flow to the conversational style of the interview.

Another limitation to this study was the disproportionate level of qualifications of participants. As only one AIN and one EN were interviewed in phase 1 this may have affected the type of data which was collected, as the knowledge bases of AINs and ENs are different than that of RNs due to their level of training, as discussed previously. If more AINs and ENs were interviewed it is possible that the findings may have had a different slant.

A further limitation is that the ACHCP who were interviewed were employed in the Brisbane metropolitan area. If ACHCP from other locations, interstate for instance, were interviewed the data collected may have provided a different picture of care at the EOL in RACFs across Australia.

The relatively small panel size may be a limitation of this study in relation to Phase 2. Although the selection criteria was that participants should have more than five years' experience in the aged care setting, there is no way to be certain that this experience was in a

direct care capacity or that their opinion was that of an expert in this area and representative of ACHCP in general. Another factor is that approximately one third of the expert panel selected from participants in round 1 did not respond in round 2 and round 3. Had they done so, and had they disagreed with the ACHCP who did respond, some of the statements may not have achieved the required consensus level of 75%. Also, use of the forced response in round 2 and round 3, may have forced participants to make a choice on some statements that they may have preferred not to make. It is possible also that the responses and experiences in this instance cast some doubt as to the suitability of the Delphi approach in EOL care situations.

Implications for Further Research

The main recommendations for future research are to establish the sensitivity of the signs and indicators to determine the early and the later phases, and to develop and refine an assessment tool which may be used by ACHCP to confirm the commencement of the EOL phase.

A retrospective analysis of the care after the death of a resident is one way that the signs and indicators could be tested to confirm their relevance to determine the EOL phase of care. In this way the sensitivity of the signs and indicators to determine both phases of the EOL could be analysed. The nursing documentation could be reviewed, after the death of a resident, to determine the frequency of the presence of each sign and indicator, described in phase 1 and confirmed in phase 2, and would add to the validity and reliability of the research results and the tool which is developed. The results of the research would be tested over time using another methodology; the aim being to provide reliable and predictable results which could be used to develop a tool which ACHCP could use to determine the EOL phase of care.

Another way this research could be further extended is to develop a daily checklist of the signs and indicators which ACHCP at various levels of qualifications and experience could use in their daily care of residents. When a resident dies, the information from the daily checklist could be reviewed retrospectively to further assess the sensitivity of the checklist,

thus identifying which of the signs and indictors are present with regard to each phase. If the presence of EOL signs and indicators is recognised and routinely documented by ACHCP it would alert them to the possibility that a resident may have entered the EOL phase of care. Therefore reassessment should be undertaken with the aim of reviewing nursing interventions in terms of their appropriateness to EOL care.

As discussed in Chapter 6, the AIN saw her role as being 'the eyes and ears' for the RN. It is important that these ACHCP are well prepared and able to recognise signs which signify the commencement of the EOL phase. Further research into the educational preparation of the AIN in the aged care setting, in particular as it relates to the EOL phase of care, may provide a clearer picture of the expectation of their role and education necessary in order that AINs are prepared to recognise a change in the health status of a resident. Thus the RN would be alerted and able to reassess the care of the resident at this time.

Another way that the results of this research could be extended would be to conduct a larger research study. As mentioned previously, this study was conducted in the Brisbane metropolitan area. This may have provided a description of the view of participants in this location but the results may be different if the study was conducted in other locations across Australia. A larger study which encompasses Australia-wide RACFs may reveal other variations of signs and indicators or might confirm those identified in this research study.

In conclusion, understanding EOL in RACFs has been enhanced with the confirmation of existing research by the results of this study. The benefits of the findings to ACHCP and residents are an early recognition of the commencement of the EOL phase resulting in the most appropriate planning of care, prevention of discomfort and support for the family.

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Australian Catholic University
Brisbane Sydney Canberra Ballarat Melbourne

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INFORMATION LETTER TO PARTICIPANTS

TITLE OF PROJECT: Nurses' recognition and interpretation of changes associated with end-of-life in a residential aged care facility.

SUPERVISOR: Professor Paul Fulbrook

STUDENT RESEARCHER: Ruth Hohn

PROGRAMME IN WHICH ENROLLED: Master of Philosophy

Dear Participant,

You are invited to participate in a research project which aims to describe certain signs that you might identify which suggest that a resident might have deteriorated and may die in the next three or four days. I will be asking you to talk with me after you have cared for a particular resident who has died.

If you agree to participate in this research, you will be invited to take part in up to three face-to-face interviews. Each interview is expected to last for approximately one hour. The face-to-face interviews will be conducted in a quiet place of your choice, away from the ward environment.

If you agree to the face-to-face interview(s), the only people present will be you and me. The questions I will be asking you will be about the things that the resident, who has recently died, may have done or said or changes in their usual condition that may have altered in the days before their death. The interview will be tape recorded and I will take some notes while you are talking.

After the initial interview you may be invited for a second interview. The purpose of this interview will be for you to expand on some of the topics you raised in the first interview. At this time you will also have the opportunity to add anything which you may have forgotten to discuss in the first interview. In some cases, to expand still further on topics that have been raised by yourself and other participants, it is possible that you might be asked to participate in a further interview.

After each interview you will be given the opportunity to read the transcript to make sure I understood what you meant and that you agree with what is written.

If you are interested in being part of this research, please indicate this by ticking the appropriate boxes at the end of this letter, cut the section off and return it to me (Ruth) in the envelope provided.

The benefits for you as an aged care nurse are unlikely to be immediate. However, it is anticipated that the information that you and your colleagues provide will result in valuable insights that could be used to help improve the care of residents and their families at their end-of-life. The findings of this research will be made available to you if you wish to read it.

You will be free to withdraw your consent at any time. If you have agreed to an initial interview but decide you do not wish to continue with a second or third interview, this will be respected. This will not disadvantage you in any way. I will respect your wishes and will not contact you again in relation to the research.

Your personal details will be kept confidential and your privacy will be respected at all times. When I transcribe the notes from an interview your name will not be used but a pseudonym will be used instead. You will be identified as informant one or informant two, for example. The place where you work will also not be named to ensure that you cannot be identified because of a story or situation which might be familiar to people you know.

It is possible that some interviews will be quite emotional, especially because I will be talking to you about a deceased resident whom you may have been close to. If, at any time, you wish to temporarily stop or postpone the interview your wishes will be respected. If, as a result of the interview, you would like to talk to someone about your feelings, a qualified counsellor has agreed to provide support to you. She will talk to you in confidence. Her details are given below, and she can be contacted from 0800 to 1700, Monday to Friday.

Mrs Jean Edwards (Counsellor Palliative Care/Bereavement)
Telephone: 37175520
Mobile: 0414669376

In accordance with section 4.6 of the NH&MRC National Statement, if at any time, during any of the interviews or focus groups, information is provided to me that relates to illegal activity or unethical behavior, I will be obliged to take the matter outside of the research. In the unlikely event that this might occur, in the first instance I will pass this information to the Nurse Unit Manager, who will help me to determine what action is necessary.

Any questions you may have which have not been made clear regarding this project should be directed to my Supervisor and/or me (Student Researcher). Our contact details are below.

Ruth Hohn (Student Researcher) Home: 07 38610013 Mobile: 0405332077
Professor Paul Fulbrook (Supervisor) Work: 07 36237420
Australia Catholic University, Brisbane.

On completion of the research, you will have the opportunity to read the report. A copy of the full research report (thesis) will be available from the Australian Catholic University library, McAuley Campus, Brisbane following completion of my studies.

This study has been approved by the Human Research Ethics Committee at Australian Catholic University.

In the event that you have any complaint or concern about the way you have been treated during the study, or if you have any query that the Supervisor and Student Researcher have not been able to satisfy, you may write to the Chair of the Human Research Ethics Committee at the address given below:

Qld Chair, HREC
c/o Research Services
Australian Catholic University
Brisbane Campus
PO Box 456
Virginia QLD 4014
Tel: 07 36237429 Fax: 07 36367328

Any complaint or concern will be treated in confidence and fully investigated and you will be informed of the outcome.

If you agree to participate in this project, please indicate this in the space provided below.

…… ……

Principal Investigator Student Researcher

Cut on dotted line and return to Ruth in the envelope provided – thank you for your interest.

……....

I _____(insert your name) am interested in being part of this research.

I would like to be involved in a face to face interview ☐

Australian Catholic University
Brisbane Sydney Canberra Ballarat Melbourne

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CONSENT FORM TO PARTICIPATE IN A FACE-TO-FACE INTERVIEW

Copy for Participant to Keep

TITLE OF PROJECT: Nurses' recognition and interpretation of changes associated with end-of-life in a residential aged care facility.

SUPERVISOR: Professor Paul Fulbrook

STUDENT RESEARCHER: Ruth Hohn

I ..... *(the participant)* have read (*or, where appropriate, have had read to me)* and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in up to three interviews, each of which may be up to one hour in duration.

During a face-to-face interview I will be asked to comment on activities which occurred during the week prior to the death of a resident whom I cared for. The interview will be audio taped and the researcher will also take notes. I will be given the opportunity to read the interview when it has been transcribed and have the opportunity to add anything which I may have overlooked initially to ensure that the meaning I intended is clear. I realise that I can withdraw my consent at any time and that the researcher will not contact me again related to this research project. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT .....

SIGNATURE ..... **DATE** .....

SIGNATURE OF PRINCIPAL SUPERVISOR .....

DATE……...

SIGNATURE OF STUDENT RESEARCHER .....

DATE .....…….....

Australian Catholic University
Brisbane Sydney Canberra Ballarat Melbourne

ACU National

CONSENT FORM TO PARTICIPATE IN A FACE-TO-FACE INTERVIEW

Copy for Researcher

TITLE OF PROJECT: Nurses' recognition and interpretation of changes associated with end-of-life in a residential aged care facility.

SUPERVISOR: Professor Paul Fulbrook

STUDENT RESEARCHER: Ruth Hohn

I ..... *(the participant)* have read (*or, where appropriate, have had read to me)* and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in up to three interviews, each of which may be up to one hour in duration.

During a face-to-face interview I will be asked to comment on activities which occurred during the week prior to the death of a resident whom I cared for. The interview will be audio taped and the researcher will also take notes. I will be given the opportunity to read the interview when it has been transcribed and have the opportunity to add anything which I may have overlooked initially to ensure that the meaning I intended is clear. I realise that I can withdraw my consent at any time and that the researcher will not contact me again related to this research project. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT .....

SIGNATURE ..... **DATE** .....

SIGNATURE OF PRINCIPAL SUPERVISOR .....

DATE ……...

SIGNATURE OF STUDENT RESEARCHER .....

DATE .....……....

Australian Catholic University
Brisbane Sydney Canberra Ballarat Melbourne

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Human Research Ethics Committee

Committee Approval Form

Principal Investigator/Supervisor: Professor Paul Fulbrook Brisbane Campus

Co-Investigators:

Student Researcher: Ms Ruth Hohn Brisbane Campus

Ethics approval has been granted for the following project:
Nurses' recognition and interpretation of changes associated with end-of-life in a residential aged care facility.

for the period: 2 May 2008 to 31 December 2008

Human Research Ethics Committee (HREC) Register Number: Q200708 7

The following standard conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans* (2007) apply:

(i) that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
- security of records
- compliance with approved consent procedures and documentation
- compliance with special conditions, and

(ii) that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
- proposed changes to the protocol
- unforeseen circumstances or events
- adverse effects on participants

The HREC will conduct an audit each year of all projects deemed to be of more than low risk. There will also be random audits of a sample of projects considered to be of negligible risk and low risk on all campuses each year.

Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Research Services Officer.

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Research Services Officer within one month of the anniversary date of the ethics approval.

K. Pashley.

Signed: Date: 2 May 2008
(Research Services Officer, McAuley Campus)

Dear Paul and Ruth,

Thank you for submitting the request to modify form for your project Q200708-7 *Nurses' recognition and interpretation of changes associated with end-of-life in a residential aged care facility.*

The Chair of the Human Research Ethics Committee has approved the following modifications:

1. Extension to 31 July 2009.
2. Extend research to include new facilities - Carrington Retirement Community, Bethesda Caring Centre, Pine Lodge Nursing Home, St Nicholas Nursing Home, Archbishop Duhig Nursing Home.
3. Written permission is required from the facilities noted above.

We wish you well in this ongoing research project.

Kind Regards,

Kylie

Kylie Pashley
Research Services
McAuley at Banyo Campus
PO Box 456
VIRGINIA QLD 4014
AUSTRALIA

Tel (+61 07) 3623 7429 Fax (+61 07) 3623 7328
EMAIL: kylie.pashley@acu.edu.au

Australian Catholic University Ltd
ABN 15 050 192 660
CRICOS Registration codes:00004G, 00112C, 00873F, 00885B

Appendix D

Q200708-7 Ethics Extension Approved

Kylie Pashley

Sent: Thursday, 26 November 2009 10:17

To: ruth Hohn [rubad@bigpond.com]; Paul Fulbrook

Dear Paul and Ruth,

Thank you for returning your ethics Modification Request for your project Q200708-7 *Nurses' recognition and interpretation of changes associated with end-of-life in a residential aged care facility.*

The Deputy Chair of the Human Research Ethics Committee has approved your request to extend the period of data collection. The new expiry date for data collection is the **31 July 2010**.

We wish you well in this ongoing project.

Kind Regards,

Kylie

Kylie Pashley
Research Services
McAuley at Banyo Campus
PO Box 456
VIRGINIA QLD 4014
AUSTRALIA
I am available Monday, Thursday and Friday.
Tel (+61 07) 3623 7429 Fax (+61 07) 3623 7328
EMAIL: kylie.pashley@acu.edu.au

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I am available Monday, Thursday and Friday.
Tel (+61 07) 3623 7429 Fax (+61 07) 3623 7328
EMAIL: kylie.pashley@acu.edu.au

End-of-life Survey

1. Welcome

Thank you very much for agreeing to participate in this Delphi Survey.

This is the first round.

The CLOSING DATE for this round is midnight 28th FEBRUARY 2010.

There are likely to be two further rounds (questionnaires), although there will be fewer questions in each round. The aim is to reach consensus agreement with each of the statements in the survey.

There are are four sections in this survey.

The first section asks some questions about you as an aged care nurse.

The following three sections comprise a series of statements about recognition of changes associated with the period prior to death of an elderly resident in a high level aged care facility.

This is the first round of the Delphi survey.

It will take approximately 30 minutes to complete.

2. Biographical details

This section contains 5 questions about your experience as an aged care nurse.

Each question must be answered prior to moving to the next section of the survey.

End-of-life Survey

*** 1. Please indicate how many years of experience you have working in residental aged care**

- ◯ Less than 2 years
- ◯ Between 2 to 5 years
- ◯ More than 5 years, but less than 10 years
- ◯ Greater than 10 years

*** 2. Please indicate your professional qualification/level:**

- ◯ Assistant in Nursing
- ◯ Enrolled Nurse
- ◯ Endorsed Enrolled Nurse
- ◯ Registered Nurse

*** 3. Please indicate below the highest level of advanced study you have completed in the last five years in the area of AGED CARE:**

- ◯ None
- ◯ Short course in Aged Care
- ◯ Certificate Aged Care
- ◯ Graduate Diploma Aged Care
- ◯ Other (please specify)

End-of-life Survey

*** 4. Please indicate below the highest level of advanced study you have completed in the last five years in the area of DEMENTIA CARE:**

- ◯ None
- ◯ Short course in Dementia Care
- ◯ Certificate Dementia Care
- ◯ Graduate Diploma Dementia Care
- ◯ Other (please specify)

*** 5. Please indicate below the highest level of advanced study you have completed in the last five years in the area of PALLIATIVE CARE:**

- ◯ None
- ◯ Short course in Palliative Care
- ◯ Certificate Palliative Care
- ◯ Graduate Diploma Palliative Care
- ◯ Other (please specify)

End-of-life Survey

*** 6. Please indicate the sector you work in:**

- ◯ Public facility
- ◯ Private facility
- ◯ Other (please describe)

*** 7. Please indicate the state/territory in which you currently practise:**

	state/territory
Select from the drop down menu	

*** 8. Please indicate your MAIN area of practice:**

	Area of practice
Select one choice from the drop down menu	

3. General overview

This section contains generalised statements about residents with high level care needs. They may have been bed bound for some months and have slowly deteriorated during this time. These factors can make identification of the end-of-life phase difficult.

Each question must be answered prior to moving on to the next section of the survey.

*** 9. Please indicate your strength of agreement with the following statement by ticking the relevant box.**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
There are definite indicators that a resident with high level care needs may die soon	◯	◯	◯	◯	◯

*** 10. Please indicate your strength of agreement with the following statement by ticking the relevant box.**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
There is an initial or pre-terminal phase of change in a resident's condition, which commences around two weeks before death	◯	◯	◯	◯	◯

End-of-life Survey

*** 11. Please indicate your strength of agreement with the following statement by ticking the relevant box.**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
There is a second or terminal phase of change in a resident's condition, which commences two to three days before death	◯	◯	◯	◯	◯

4. Signs of an early change.

Phase one of this research study indicated that there are several early changes in the usual condition of the resident, around two weeks prior to death, that are associated with their transition to an end-of-life phase.

This section of the survey asks questions about this EARLY PHASE.

Please note that each question MUST be answered prior to moving on to the next section of the survey.

*** 12. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A change associated with the early phase is a recent decreased appetite, where the resident may not be able or willing to eat.	◯	◯	◯	◯	◯

*** 13. Please indicate below your strength of agreement with the indicators of a decreased appetite by ticking the relevant box.**

In the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
The resident has often started to spit food out	◯	◯	◯	◯	◯
The resident has recently started to drool	◯	◯	◯	◯	◯
The resident's swallow has deteriorated recently	◯	◯	◯	◯	◯
The resident has a recent significant weight loss	◯	◯	◯	◯	◯

*** 14. Please indicate below your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A change associated with the early phase is that the resident becomes suddenly more frail.	◯	◯	◯	◯	◯

End-of-life Survey

*** 15. Please indicate below your strength of agreement with the indicators of increased frailty by ticking the relevant box.**

In the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
The resident's physical capacity has decreased significantly	◯	◯	◯	◯	◯
The resident has recently been unable to assist with usual activities and has become weaker	◯	◯	◯	◯	◯

*** 16. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Stongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A change associated with the early phase is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations.	◯	◯	◯	◯	◯

*** 17. Please indicate below your strength of agrement with indicators of becoming more withdrawn by ticking the relevant box.**

In the the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Recently, the resident does not seem to recognise once familiar people	◯	◯	◯	◯	◯
The resident has recently developed a faraway or vacant look	◯	◯	◯	◯	◯
The resident has recently developed limited or no verbal interaction	◯	◯	◯	◯	◯

*** 18. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Stongly Disagree	Disagree	Unsure	Agree	Strongly Agree
To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, all three conditions of: recent decreased appetite, sudden increased frailty, and recent acute withdrawal must be present.	◯	◯	◯	◯	◯

5. Changes that may been seen later.

The findings from phase 1 of this research study suggested that some signs may be seen at a later phase, two or three days prior to death. At this time, there are several changes in the usual condition of the resident.

End-of-life Survey

This section of the survey asks questions abouth this LATER PHASE.

Each question MUST be answered prior to moving on to the next section of the survey.

*** 19. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A very recent change in the usual condition of the resident which may be associated with a later phase is a change to the usual skin colour.	◯	◯	◯	◯	◯

*** 20. Please indicate below your strength of agreement with indicators of skin changes by ticking the relevant box.**

In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
The resident's skin has recently marked or discoloured on the side they were lying	◯	◯	◯	◯	◯
The resident's skin has recently become mottled	◯	◯	◯	◯	◯

*** 21. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A very recent change in the usual condition of the resident which may be associated with a later phase is poor peripheral circulation.	◯	◯	◯	◯	◯

*** 22. Please indicate below your strength of agreement with the indicators of circulation shutting down by ticking the relevant box.**

In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Recently the resident's skin has become a dusky, grey colour.	◯	◯	◯	◯	◯
Recently, the resident's extremeties, hands, feet, ears, lips or nose are a bluish colour.	◯	◯	◯	◯	◯

*** 23. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A very recent change to the usual condition of the resident which may be associated with a later phase is a change to their usual breathing pattern	◯	◯	◯	◯	◯

End-of-life Survey

*** 24. Please indicate below your strength of agreement with the indicators of breathing changes by ticking the relevant box.**

In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
The resident has recently developed apnoea or periods of no breaths which did not occur before this time.	◯	◯	◯	◯	◯
The resident has recently developed dyspnoea or difficulty breathing which did not occur before this time.	◯	◯	◯	◯	◯
The resident has recently developed a moist chest or rattling breathing which did not occur before this time.	◯	◯	◯	◯	◯

*** 25. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A very recent change to the usual condition of the resident which may be associated with a later phase is sudden increased pain on movement. This may be a sudden worsening of pain which was present already or a new acute event.	◯	◯	◯	◯	◯

*** 26. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, all four conditions of: changes to the usual skin colour, poor peripheral circulation, changes to the usual breathing pattern, and sudden increased pain on movement must be present.	◯	◯	◯	◯	◯

6. Thank you

Thank you for participating in Round 1 of this Delphi survey.

When all responses have been received they will be analysed. The statements that achieve consensus in this round will be removed from subsequent rounds.

In the next round, you will be informed of the overall level of agreement with the statements in Round 1, and you will be asked whether you would like to conform to the majority view.

In this way, the survey will proceed until all, or most, statements achieve consensus agreement.

End-of-life Survey

*** 27. Please indicate if you are willing to participate in subsequent rounds of this Delphi study**

- ◯ No
- ◯ Yes: please provide an email address for futher surveys to be sent directly to you

Pilot End-of-Life Survey

1. Welcome

Thank you very much for agreeing to participate in this pilot survey about recognition of changes associated with end-of-life.

The purpose of this pilot study is to find out whether the questions are clear and understandable, to gauge how long it takes to complete the survey, and to identify any relevant areas of inquiry that may not have been considered.

I would like you to complete the survey as honestly as you can. However, I will not be using your answers as part of my main study.

As you go through each section of the survey, please make notes about any of the questions. At the end of the survey there is a section that asks about the survey itself. Any comments you provide will be very helpful to me, and may be used to modify the survey.

There are are four sections in this survey.

The first section asks some questions about you as an aged care nurse.

The following three sections comprise a series of statements about recognition of changes associated with the period prior to death of an elderly resident in a high level aged care facility.

The final section asks questions about the survey itself.

Thank you very much for taking the time to participate in this pilot suvey. Your help is very much appreciated.

THANK YOU.

Ruth

2. Biographical details

This section contains 5 questions about your experience as an aged care nurse.

Each question must be answered prior to moving to the next section of the survey.

Pilot End-of-Life Survey

*** 1. Please indicate how many years of experience you have working in residental aged care**

- ◯ 2 to 5 years
- ◯ > 5 to 10 years
- ◯ > 10 years

*** 2. Please indicate your professional qualification/level:**

- ◯ Assistant in Nursing
- ◯ Enrolled Nurse
- ◯ Endorsed Enrolled Nurse
- ◯ Registered Nurse

*** 3. Please indicate below the highest level of advanced study you have completed in the last five years in the area of AGED CARE:**

- ◯ Short course in Aged Care
- ◯ Certificate Aged Care
- ◯ Graduate Diploma Aged Care

Other (please specify)

Pilot End-of-Life Survey

*** 4. Please indicate below the highest level of advanced study you have completed in the last five years in the area of DEMENTIA CARE:**

- ◯ Short course in Dementia Care
- ◯ Certificate Dementia Care
- ◯ Graduate Diploma Dementia Care

Other (please specify)

*** 5. Please indicate below the highest level of advanced study you have completed in the last five years in the area of PALLIATIVE CARE:**

- ◯ Short course in Palliative Care
- ◯ Certificate Palliative Care
- ◯ Graduate Diploma Palliative Care

Other (please specify)

*** 6. Please indicate the sector you work in:**

- ◯ Public facility
- ◯ Private facility

*** 7. Please indicate the state/territory in which you currently practise:**

	state/territory
Select from the drop down menu	

Pilot End-of-Life Survey

*** 8. Please indicate your MAIN area of practice:**

	Area of practice
Select one choice from the drop down menu	

3. General overview

This section contains generalised statements about residents with high level care needs. They may have been bed bound for some months and have slowly deteriorated during this time. These factors can make identification of the end-of-life phase difficult.

Each question must be answered prior to moving on to the next section of the survey.

*** 9. Please indicate your strength of agreement with the following statement by ticking the relevant box.**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
There are definite indicators that a resident with high level care needs may die soon	◯	◯	◯	◯	◯

*** 10. Please indicate your strength of agreement with the following statement by ticking the relevant box.**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
There is an initial or pre-terminal phase of change in a resident's condition, which commences around two weeks before death	◯	◯	◯	◯	◯

*** 11. Please indicate your strength of agreement with the following statement by ticking the relevant box.**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
There is a second or terminal phase of change in a resident's condition, which commences two to three days before death	◯	◯	◯	◯	◯

4. Signs of an early change.

Phase one of this research study indicated that there are several early changes in the usual condition of the resident, around two weeks prior to death, that are associated with their transition to an end-of-life phase.

This section of the survey asks questions about this EARLY PHASE.
Please note that each question MUST be answered prior to moving on to the next section of the survey.

Pilot End-of-Life Survey

*** 12. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A change associated with the early phase is a recent decreased appetite, where the resident may not be able or willing to eat.	◯	◯	◯	◯	◯

*** 13. Please indicate below your strength of agreement with the indicators of a decreased appetite by ticking the relevant box.**

In the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
The resident has often started to spit food out	◯	◯	◯	◯	◯
The resident has recently started to drool	◯	◯	◯	◯	◯
The resident's swallow has detriorated recently	◯	◯	◯	◯	◯
The resident has a recent significant weight loss	◯	◯	◯	◯	◯

*** 14. Please indicate below your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A change associated with the early phase is that the resident becomes suddenly more frail.	◯	◯	◯	◯	◯

*** 15. Please indicate below your strength of agreement with the indicators of increased frailty by ticking the relevant box.**

In the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
The resident's physical capacity has decreased significantly	◯	◯	◯	◯	◯
The resident has recently been unable to assist with usual activities and has become weaker	◯	◯	◯	◯	◯

*** 16. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Stongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A change associated with the early phase is that the resident has recently become acutely withdrawn and does not interact in the usual way with familiar people and situations.	◯	◯	◯	◯	◯

Pilot End-of-Life Survey

*** 17. Please indicate below your strength of agrement with indicators of becoming more withdrawn by ticking the relevant box.**

In the the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Recently, the resident does not seem to recognise once familiar people	◯	◯	◯	◯	◯
The resident has recently developed a faraway or vacant look	◯	◯	◯	◯	◯
The resident has recently developed limited or no verbal interaction	◯	◯	◯	◯	◯

*** 18. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Stongly Disagree	Disagree	Unsure	Agree	Strongly Agree
To confirm that the resident has entered the early phase of change associated with the end-of-life phase, all three conditions of: recent decreased appetite, sudden increased frailty, and recent acute withdrawl must be present.	◯	◯	◯	◯	◯

5. Changes that may been seen later.

The findings from phase 1 of this research study suggested that some signs may be seen at a later phase, two or three days prior to death. At this time, there are several changes in the usual condition of the resident.

This section of the survey asks questions abouth this LATER PHASE.

Each question MUST be answered prior to moving on to the next section of the survey.

*** 19. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A very recent change in the usual condition of the resident which may be associated with a later phase is a change to the usual skin colour.	◯	◯	◯	◯	◯

Pilot End-of-Life Survey

*** 20. Please indicate below your strength of agreement with indicators of skin changes by ticking the relevant box.**

In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
The resident's skin has recently marked or discoloured on the side they were lying	◯	◯	◯	◯	◯
The resident's skin has recently become mottled	◯	◯	◯	◯	◯

*** 21. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A very recent change in the usual condition of the resident which may be associated with a later phase is poor peripheral circulation.	◯	◯	◯	◯	◯

*** 22. Please indicate below your strength of agreement with the indicators of circulation shutting down by ticking the relevant box.**

In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Recently the resident's skin has become a dusky, grey colour.	◯	◯	◯	◯	◯
Recently, the resident's extremeties, hands, feet, ears, lips or nose are a bluish colour.	◯	◯	◯	◯	◯

*** 23. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A very recent change to the usual condition of the resident which may be associated with a later phase are changes to their usual breathing pattern	◯	◯	◯	◯	◯

Pilot End-of-Life Survey

*** 24. Please indicate below your strength of agreement with the indicators of breathing changes by ticking the relevant box.**

In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
The resident has recently developed apnoea or periods of no breaths which did not occur before this time.	◯	◯	◯	◯	◯
The resident has recently developed dyspnoea or difficulty breathing which did not occur before this time.	◯	◯	◯	◯	◯
The resident has recently developed a moist chest or rattling breathing which did not occur before this time.	◯	◯	◯	◯	◯

*** 25. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
A very recent change to the usual condition of the resident which may be associated with a later phase is sudden increased pain on movement. This may be a sudden worsening of pain which was present already or a new acute event.	◯	◯	◯	◯	◯

*** 26. Please indicate your strength of agreement with the following statement by ticking the relevant box**

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
To confirm that the resident has entered a later phase of change associated with the end-of-life phase, all four conditions of: changes to the usual skin colour, poor peripheral circulation, changes to the usual breathing pattern, and sudden increased pain on movement must be present.	◯	◯	◯	◯	◯

6. Completion of survey

Thank you so much for completing this survey.

As you have been part of the pilot group some additional questions about using the survey have been added.

I appreciate any comments you make to ensure this survey is easy to use and therefore the data collected is accurate.

Pilot End-of-Life Survey

27. Did you find the survey easy to navigate?

- ◯ Yes
- ◯ No
- ◯ Unsure

Please feel free to add comments here

28. Did you find the order of the questions helpful?

- ◯ Yes
- ◯ No
- ◯ Unsure

Please feel free to add your comments here

Pilot End-of-Life Survey

29. Did you find the questions were easy to understand?

- ◯ Yes
- ◯ No
- ◯ Unsure

Please feel free to add your comments here

30. Are there any questions that you think could have been worded better? If so, please make suggestions below.

31. How long did the survey take to complete?

- ◯ less than 15 minutes
- ◯ 15-30 minutes
- ◯ 31-45 minutes
- ◯ longer (please specify below)

Number of minutes, if greater than 45

Pilot End-of-Life Survey

32. Please add any other comments about the survey or the contents here.

End-of-life Survey

1. Please indicate how many years of experience you have working in residental aged care

	Response Percent	Response Count
Less than 2 years	5.0%	2
Between 2 to 5 years	10.0%	4
More than 5 years, but less than 10 years	35.0%	14
Greater than 10 years	**50.0%**	**20**
answered question		**40**
skipped question		**1**

2. Please indicate your professional qualification/level:

	Response Percent	Response Count
Assistant in Nursing	2.5%	1
Enrolled Nurse	7.5%	3
Endorsed Enrolled Nurse	2.5%	1
Registered Nurse	**87.5%**	**35**
answered question		**40**
skipped question		**1**

3. Please indicate below the highest level of advanced study you have completed in the last five years in the area of AGED CARE:

	Response Percent	Response Count
None	25.0%	10
Short course in Aged Care	27.5%	11
Certificate Aged Care	7.5%	3
Graduate Diploma Aged Care	2.5%	1
Other (please specify)	**37.5%**	**15**
answered question		**40**
skipped question		**1**

4. Please indicate below the highest level of advanced study you have completed in the last five years in the area of DEMENTIA CARE:

	Response Percent	Response Count
None	22.5%	9
Short course in Dementia Care	**52.5%**	**21**
Certificate Dementia Care	12.5%	5
Graduate Diploma Dementia Care	5.0%	2
Other (please specify)	7.5%	3
answered question		**40**
skipped question		**1**

5. Please indicate below the highest level of advanced study you have completed in the last five years in the area of PALLIATIVE CARE:

	Response Percent	Response Count
None	20.0%	8
Short course in Palliative Care	**50.0%**	**20**
Certificate Palliative Care	17.5%	7
Graduate Diploma Palliative Care	5.0%	2
Other (please specify)	7.5%	3
answered question		**40**
skipped question		**1**

6. Please indicate the sector you work in:

	Response Percent	Response Count
Public facility	10.0%	4
Private facility	**75.0%**	**30**
Other (please describe)	15.0%	6
answered question		**40**
skipped question		**1**

7. Please indicate the state/territory in which you currently practise:

state/territory

	ACT	NSW	NT	Qld	SA	Tas	Vic	WA	Response Count
Select from the drop down menu	0.0% (0)	25.0% (10)	0.0% (0)	22.5% (9)	**32.5% (13)**	0.0% (0)	2.5% (1)	17.5% (7)	40
								answered question	**40**
								skipped question	**1**

8. Please indicate your MAIN area of practice:

Area of practice

	Administration	Clinical	Education	Management	Research	Response Count
Select one choice from the drop down menu	5.0% (2)	**42.5% (17)**	10.0% (4)	40.0% (16)	2.5% (1)	40
					answered question	**40**
					skipped question	**1**

9. Please indicate your strength of agreement with the following statement by ticking the relevant box.

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
There are definite indicators that a resident with high level care needs may die soon	0.0% (0)	7.9% (3)	0.0% (0)	**60.5% (23)**	31.6% (12)	4.16	38
						answered question	**38**
						skipped question	**3**

10. Please indicate your strength of agreement with the following statement by ticking the relevant box.

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
There is an initial or pre-terminal phase of change in a resident's condition, which commences around two weeks before death	0.0% (0)	21.1% (8)	26.3% (10)	**47.4% (18)**	5.3% (2)	3.37	38
						answered question	**38**
						skipped question	**3**

11. Please indicate your strength of agreement with the following statement by ticking the relevant box.

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
There is a second or terminal phase of change in a resident's condition, which commences two to three days before death	0.0% (0)	5.3% (2)	15.8% (6)	**65.8% (25)**	13.2% (5)	3.87	38
						answered question	**38**
						skipped question	**3**

12. Please indicate your strength of agreement with the following statement by ticking the relevant box

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
A change associated with the early phase is a recent decreased appetite, where the resident may not be able or willing to eat.	0.0% (0)	6.3% (2)	6.3% (2)	**65.6% (21)**	21.9% (7)	4.03	32
						answered question	**32**
						skipped question	**9**

13. Please indicate below your strength of agreement with the indicators of a decreased appetite by ticking the relevant box. In the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
The resident has often started to spit food out	0.0% (0)	23.3% (7)	16.7% (5)	**46.7% (14)**	13.3% (4)	3.50	30
The resident has recently started to drool	0.0% (0)	33.3% (10)	26.7% (8)	**40.0% (12)**	0.0% (0)	3.07	30
The resident's swallow has deteriorated recently	0.0% (0)	9.7% (3)	3.2% (1)	**80.6% (25)**	6.5% (2)	3.84	31
The resident has a recent significant weight loss	0.0% (0)	13.3% (4)	6.7% (2)	**66.7% (20)**	13.3% (4)	3.80	30
						answered question	**32**
						skipped question	**9**

14. Please indicate below your strength of agreement with the following statement by ticking the relevant box

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
A change associated with the early phase is that the resident becomes suddenly more frail.	0.0% (0)	15.6% (5)	6.3% (2)	**68.8% (22)**	9.4% (3)	3.72	32
						answered question	**32**
						skipped question	**9**

15. Please indicate below your strength of agreement with the indicators of increased frailty by ticking the relevant box. In the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
The resident's physical capacity has decreased significantly	0.0% (0)	9.7% (3)	3.2% (1)	**67.7% (21)**	19.4% (6)	3.97	31
The resident has recently been unable to assist with usual activities and has become weaker	0.0% (0)	6.9% (2)	3.4% (1)	**72.4% (21)**	17.2% (5)	4.00	29
						answered question	**32**
						skipped question	**9**

16. Please indicate your strength of agreement with the following statement by ticking the relevant box

	Stongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
A change associated with the early phase is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations.	0.0% (0)	21.9% (7)	21.9% (7)	**46.9% (15)**	9.4% (3)	3.44	32
						answered question	**32**
						skipped question	**9**

17. Please indicate below your strength of agrement with indicators of becoming more withdrawn by ticking the relevant box. In the the early phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
Recently, the resident does not seem to recognise once familiar people	10.0% (3)	**53.3% (16)**	16.7% (5)	20.0% (6)	0.0% (0)	2.47	30
The resident has recently developed a faraway or vacant look	3.3% (1)	26.7% (8)	20.0% (6)	**43.3% (13)**	6.7% (2)	3.23	30
The resident has recently developed limited or no verbal interaction	0.0% (0)	28.1% (9)	18.8% (6)	**53.1% (17)**	0.0% (0)	3.25	32
						answered question	**32**
						skipped question	**9**

18. Please indicate your strength of agreement with the following statement by ticking the relevant box

	Stongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, all three conditions of: recent decreased appetite, sudden increased frailty, and recent acute withdrawal must be present.	3.1% (1)	**46.9% (15)**	12.5% (4)	37.5% (12)	0.0% (0)	2.84	32
						answered question	**32**
						skipped question	**9**

19. Please indicate your strength of agreement with the following statement by ticking the relevant box

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
A very recent change in the usual condition of the resident which may be associated with a later phase is a change to the usual skin colour.	0.0% (0)	3.4% (1)	10.3% (3)	**75.9% (22)**	10.3% (3)	3.93	29
						answered question	**29**
						skipped question	**12**

20. Please indicate below your strength of agreement with indicators of skin changes by ticking the relevant box. In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
The resident's skin has recently marked or discoloured on the side they were lying	4.0% (1)	4.0% (1)	0.0% (0)	**76.0% (19)**	16.0% (4)	3.96	25
The resident's skin has recently become mottled	3.4% (1)	0.0% (0)	10.3% (3)	**72.4% (21)**	13.8% (4)	3.93	29
						answered question	**29**
						skipped question	**12**

21. Please indicate your strength of agreement with the following statement by ticking the relevant box

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
A very recent change in the usual condition of the resident which may be associated with a later phase is poor peripheral circulation.	0.0% (0)	0.0% (0)	0.0% (0)	**82.8% (24)**	17.2% (5)	4.17	29
						answered question	**29**
						skipped question	**12**

22. Please indicate below your strength of agreement with the indicators of circulation shutting down by ticking the relevant box. In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
Recently the resident's skin has become a dusky, grey colour.	0.0% (0)	7.4% (2)	3.7% (1)	**81.5% (22)**	7.4% (2)	3.89	27
Recently, the resident's extremeties, hands, feet, ears, lips or nose are a bluish colour.	0.0% (0)	0.0% (0)	3.4% (1)	**86.2% (25)**	10.3% (3)	4.07	29
						answered question	**29**
						skipped question	**12**

23. Please indicate your strength of agreement with the following statement by ticking the relevant box

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
A very recent change to the usual condition of the resident which may be associated with a later phase is a change to their usual breathing pattern	0.0% (0)	3.4% (1)	0.0% (0)	**72.4% (21)**	24.1% (7)	4.17	29
						answered question	**29**
						skipped question	**12**

24. Please indicate below your strength of agreement with the indicators of breathing changes by ticking the relevant box. In the later phase:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
The resident has recently developed apnoea or periods of no breaths which did not occur before this time.	0.0% (0)	3.6% (1)	0.0% (0)	**71.4% (20)**	25.0% (7)	4.18	28
The resident has recently developed dyspnoea or difficulty breathing which did not occur before this time.	0.0% (0)	3.6% (1)	14.3% (4)	**71.4% (20)**	10.7% (3)	3.89	28
The resident has recently developed a moist chest or rattling breathing which did not occur before this time.	0.0% (0)	3.4% (1)	0.0% (0)	**79.3% (23)**	17.2% (5)	4.10	29
					answered question		**29**
					skipped question		**12**

25. Please indicate your strength of agreement with the following statement by ticking the relevant box

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
A very recent change to the usual condition of the resident which may be associated with a later phase is sudden increased pain on movement. This may be a sudden worsening of pain which was present already or a new acute event.	0.0% (0)	13.8% (4)	10.3% (3)	**65.5% (19)**	10.3% (3)	3.72	29
						answered question	**29**
						skipped question	**12**

26. Please indicate your strength of agreement with the following statement by ticking the relevant box

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Rating Average	Response Count
To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, all four conditions of: changes to the usual skin colour, poor peripheral circulation, changes to the usual breathing pattern, and sudden increased pain on movement must be present.	0.0% (0)	**48.3% (14)**	3.4% (1)	41.4% (12)	6.9% (2)	3.07	29
						answered question	**29**
						skipped question	**12**

27. Please indicate if you are willing to participate in subsequent rounds of this Delphi study

	Response Percent	Response Count
No	13.8%	4
Yes: please provide an email address for futher surveys to be sent directly to you	**86.2%**	**25**
answered question		**29**
skipped question		**12**

1. In Round 1, the MAJORITY (52.7%) AGREED with the following statement in relation to an EARLY PHASE of change: There is an initial or pre-terminal phase of change in a resident's condition, which commences around two weeks before death. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 0% Disagree 21.1% Unsure 26.3% Agree 47.4% Strongly agree 5.3% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
There is an initial or pre-terminal phase of change in a resident's condition, which commences around two weeks before death.	0.0% (0)	7.7% (1)	**92.3% (12)**	0.0% (0)	2.92	13
					Comments:	2
					answered question	**13**
					skipped question	**0**

2. In Round 1, the MAJORITY (60%) AGREED with the following statement in relation to the indicators of a decreased appetite in the EARLY PHASE: The resident has often started to spit food out. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 0% Disagree 23.3% Unsure 16.7% Agree 46.7% Strongly agree 13.3% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE an indicator of a decreased appetite is:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
The resident has often started to spit food out.	0.0% (0)	15.4% (2)	**84.6% (11)**	0.0% (0)	2.85	13
					Comments:	2
					answered question	**13**
					skipped question	**0**

3. In Round 1, the MAJORITY (40%) AGREED with the following statement in relation to indicators of a decreased appetite in the EARLY PHASE: The resident has recently started to drool. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 0% Disagree 33.3% Unsure 26.7% Agree 40.0% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE an indicator of a decreased appetite is:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
The resident has recently started to drool.	0.0% (0)	**53.8% (7)**	46.2% (6)	0.0% (0)	2.46	13
					Comments:	0
					answered question	**13**
					skipped question	**0**

4. In Round 1, the MAJORITY (56.6%) AGREED with the following statement: A change associated with the EARLY PHASE is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 0% Disagree 21.9% Unsure 21.9% Agree 46.9% Strongly agree 9.4% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
A change associated with the early phase is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations.	0.0% (0)	7.7% (1)	**84.6% (11)**	7.7% (1)	3.00	13
					Comments:	2
					answered question	**13**
					skipped question	**0**

5. In Round 1, the MAJORITY (63.3%) DISAGREED with the following statement in relation to indicators of becoming more withdrawn in the EARLY PHASE. Recently, the resident does not seem to recognise once familiar people. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 10.0% Disagree 53.3% Unsure 16.7% Agree 20.0% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE an indicator of becoming more withdrawn is:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
Recently, the resident does not seem to recognise once familiar people.	7.7% (1)	**76.9% (10)**	15.4% (2)	0.0% (0)	2.08	13
					Comments:	0
					answered question	**13**
					skipped question	**0**

6. In Round 1, the MAJORITY (50%) AGREED with the following statement in relation to indicators of becoming more withdrawn in the EARLY PHASE: The resident has recently developed a faraway or vacant look. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 3.3% Disagree 26.7% Unsure 20.0% Agree 43.3% Strongly agree 6.7% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE an indicator of becoming more withdrawn is:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
The resident has recently developed a faraway or vacant look.	0.0% (0)	0.0% (0)	**100.0% (13)**	0.0% (0)	3.00	13
					Comments:	0
					answered question	**13**
					skipped question	**0**

7. In Round 1, the MAJORITY (53.1%) AGREED with the following statement in relation to the indicators of becoming more withdrawn in the EARLY PHASE: The resident has recently developed limited or no verbal interaction. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 0% Disagree 28.1% Unsure 18.8% Agree 53.1% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE an indicator of becoming more withdrawn is:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
The resident has recently developed limited or no verbal interaction.	0.0% (0)	7.7% (1)	**92.3% (12)**	0.0% (0)	2.92	13
					Comments:	1
					answered question	**13**
					skipped question	**0**

8. In Round 1, the MAJORITY (50%) DISAGREED with the following statement: To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, all three conditions of: recent decreased appetite, sudden increased frailty and recent acute withdrawal must be present. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 3.1% Disagree 46.9% Unsure 12.5% Agree 37.5% Strongly agree 0% Please indicate your strength of agreement with the following statement by ticking the relevant box. To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, please indicate below all conditions which apply:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
Recent decreased appetite	0.0% (0)	15.4% (2)	**61.5% (8)**	23.1% (3)	3.08	13
Sudden increased frailty	0.0% (0)	25.0% (3)	**58.3% (7)**	16.7% (2)	2.92	12
Recent acute withdrawal	0.0% (0)	46.2% (6)	**53.8% (7)**	0.0% (0)	2.54	13
					Comments:	1
					answered question	**13**
					skipped question	**0**

9. In Round 1, opinion was divided equally: 48.3% DISAGREED and 48.3% AGREED with the following statement: To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, all four conditions of: changes to the usual skin colour, poor peripheral circulation, changes to the usual breathing pattern and sudden increased pain on movement must be present. The required consensus level of 75% was not achieved. The responses were: Strongly disagree 0% Disagree 48.3% Unsure 3.4% Agree 41.4% Strongly agree 6.9% Please indicate your strength of agreement with the following statement by ticking the relevant box. To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, please indicate below all conditions which apply:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
Changes to the usual skin colour	0.0% (0)	15.4% (2)	**76.9% (10)**	7.7% (1)	2.92	13
Poor peripheral circulation	0.0% (0)	8.3% (1)	**75.0% (9)**	16.7% (2)	3.08	12
Changes to the usual breathing pattern	0.0% (0)	0.0% (0)	**76.9% (10)**	23.1% (3)	3.23	13
Sudden increased pain on movement	0.0% (0)	41.7% (5)	**58.3% (7)**	0.0% (0)	2.58	12
					Comments:	0
					answered question	**13**
					skipped question	**0**

1. In Round 2, the MAJORITY DISAGREED (53.8%) with the following statement in relation to indicators of a decreased appetite in the EARLY PHASE or pre-terminal phase around two weeks before death: The resident has recently started to drool. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 0% Disagree 58.3% Agree 46.2% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE an indicator of a decreased appetite is:

	Disagree	Agree	Rating Average	Response Count
The resident has recently started to drool.	**76.9% (10)**	23.1% (3)	1.23	13
			Comments:	4
			answered question	**13**
			skipped question	**0**

2. In Round 2, the MAJORITY AGREED that indicators of the EARLY PHASE of change associated with the end-of-life phase were Recent Decreased Appetite and Sudden Increased Frailty but were undecided with Recent Acute Withdrawal as the third indicator of the EARLY PHASE of change. However the required consensus level of 75% was not achieved. The responses to Recent Acute Withdrawal as an indicator of a change associated with the EARLY PHASE were: Strongly disagree 0% Disagree 46.2% Agree 53.8% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box:

	Disagree	Agree	Rating Average	Response Count
An indicator which confirms that a resident has entered an EARLY PHASE of change associated with the end-of-life phase is Recent Acute Withdrawal.	38.5% (5)	**61.5% (8)**	1.62	13
			Comments:	2
			answered question	**13**
			skipped question	**0**

3. In Round 2, the MAJORITY AGREED with the indicators which confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase are: changes to the usual skin colour, poor peripheral circulation and changes to the usual breathing pattern but were unsure about sudden increased pain on movement as the forth indicator of this phase. The required consensus level of 75% was not achieved. The responses were to Sudden Increased Pain on Movement as an indicator of a change associated with the LATER PHASE were: Strongly disagree 0% Disagree 41.7% Agree 58.3% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box.

	Disagree	Agree	Rating Average	Response Count
An indicator which confirms that a resident has entered a LATER PHASE of change associated with the end-of-life phase is Sudden Increased Pain on Movement.	38.5% (5)	**61.5% (8)**	1.62	13
			Comments:	2
			answered question	**13**
			skipped question	**0**

1. In Round 2, the MAJORITY DISAGREED (53.8%) with the following statement in relation to indicators of a decreased appetite in the EARLY PHASE or pre-terminal phase around two weeks before death: The resident has recently started to drool. However the required consensus level of 75% was not achieved. The responses were: Strongly disagree 0% Disagree 58.3% Agree 46.2% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box. In the EARLY PHASE an indicator of a decreased appetite is:

	Disagree	Agree	Rating Average	Response Count
The resident has recently started to drool.	**76.9% (10)**	23.1% (3)	1.23	13
			Comments:	4
			answered question	**13**
			skipped question	**0**

2. In Round 2, the MAJORITY AGREED that indicators of the EARLY PHASE of change associated with the end-of-life phase were Recent Decreased Appetite and Sudden Increased Frailty but were undecided with Recent Acute Withdrawal as the third indicator of the EARLY PHASE of change. However the required consensus level of 75% was not achieved. The responses to Recent Acute Withdrawal as an indicator of a change associated with the EARLY PHASE were: Strongly disagree 0% Disagree 46.2% Agree 53.8% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box:

	Disagree	Agree	Rating Average	Response Count
An indicator which confirms that a resident has entered an EARLY PHASE of change associated with the end-of-life phase is Recent Acute Withdrawal.	38.5% (5)	**61.5% (8)**	1.62	13
			Comments:	2
			answered question	**13**
			skipped question	**0**

3. In Round 2, the MAJORITY AGREED with the indicators which confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase are: changes to the usual skin colour, poor peripheral circulation and changes to the usual breathing pattern but were unsure about sudden increased pain on movement as the forth indicator of this phase. The required consensus level of 75% was not achieved. The responses were to Sudden Increased Pain on Movement as an indicator of a change associated with the LATER PHASE were: Strongly disagree 0% Disagree 41.7% Agree 58.3% Strongly agree 0% In the light of the above results, would you consider conforming to the majority view? Please indicate your strength of agreement with the following statement by ticking the relevant box.

	Disagree	Agree	Rating Average	Response Count
An indicator which confirms that a resident has entered a LATER PHASE of change associated with the end-of-life phase is Sudden Increased Pain on Movement.	38.5% (5)	**61.5% (8)**	1.62	13
			Comments:	2
			answered question	**13**
			skipped question	**0**

End-of-life Delphi Survey Round 2

1. Welcome

Thank you very much for agreeing to participate in Round 2 of this Delphi Survey. As in Round 1, this survey comprises a series of statements about recognition of changes associated with the period prior to death of an elderly resident in a high level aged care facility.

In this round, only Round 1 participants with five or more years' experience in aged care nursing are being invited to participate.

The CLOSING DATE for this round is midnight 16th APRIL 2010.

There is likely to be one final round (questionnaire) after this round of questions. The aim is to reach consensus agreement with each of the statements in the survey.

In Round 1, most statements achieved consensus, so these have been excluded from this round.

The purpose of Round 2 is to achieve consensus for the statements that did not achieve consensus in Round 1.

To help you make up your mind, the results from Round 1 are provided against each statement. However, this time the "Unsure" value has been removed from your possible responses.

Round 2 will take no more than 15 minutes to complete.

2. Round 2 Statements

This section contains generalised statements about residents with high level care needs. They may have been bed bound for some months and have slowly deteriorated during this time. These factors can make identification of the end-of-life phase difficult.

The Round 1 levels of agreement have been provided for each statement. The purpose of this is to help you decide whether or not to go with the majority view.

Each statement must be responded to prior to moving on to the next section of the survey.

End-of-life Delphi Survey Round 2

*** 1. In Round 1, the MAJORITY (52.7%) AGREED with the following statement in relation to an EARLY PHASE of change:**

There is an initial or pre-terminal phase of change in a resident's condition, which commences around two weeks before death.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 0%
Disagree 21.1%
Unsure 26.3%
Agree 47.4%
Strongly agree 5.3%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box.

In the EARLY PHASE:

	Strongly Disagree	Disagree	Agree	Strongly Agree
There is an initial or pre-terminal phase of change in a resident's condition, which commences around two weeks before death.	◯	◯	◯	◯

Comments:

End-of-life Delphi Survey Round 2

* **2. In Round 1, the MAJORITY (60%) AGREED with the following statement in relation to the indicators of a decreased appetite in the EARLY PHASE:**

The resident has often started to spit food out.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 0%
Disagree 23.3%
Unsure 16.7%
Agree 46.7%
Strongly agree 13.3%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box.

In the EARLY PHASE an indicator of a decreased appetite is:

	Strongly Disagree	Disagree	Agree	Strongly Agree
The resident has often started to spit food out.	◯	◯	◯	◯

Comments:

End-of-life Delphi Survey Round 2

*** 3. In Round 1, the MAJORITY (40%) AGREED with the following statement in relation to indicators of a decreased appetite in the EARLY PHASE:**

The resident has recently started to drool.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 0%
Disagree 33.3%
Unsure 26.7%
Agree 40.0%
Strongly agree 0%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box.

In the EARLY PHASE an indicator of a decreased appetite is:

	Strongly Disagree	Disagree	Agree	Strongly Agree
The resident has recently started to drool.	◯	◯	◯	◯

Comments:

End-of-life Delphi Survey Round 2

*** 4. In Round 1, the MAJORITY (56.6%) AGREED with the following statement:**

A change associated with the EARLY PHASE is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 0%
Disagree 21.9%
Unsure 21.9%
Agree 46.9%
Strongly agree 9.4%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box.

In the EARLY PHASE:

	Strongly Disagree	Disagree	Agree	Strongly Agree
A change associated with the early phase is that the resident has recently become withdrawn and does not interact in the usual way with familiar people and situations.	◯	◯	◯	◯

Comments:

End-of-life Delphi Survey Round 2

*** 5. In Round 1, the MAJORITY (63.3%) DISAGREED with the following statement in relation to indicators of becoming more withdrawn in the EARLY PHASE.**

Recently, the resident does not seem to recognise once familiar people.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 10.0%
Disagree 53.3%
Unsure 16.7%
Agree 20.0%
Strongly agree 0%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box.

In the EARLY PHASE an indicator of becoming more withdrawn is:

	Strongly Disagree	Disagree	Agree	Strongly Agree
Recently, the resident does not seem to recognise once familiar people.	◯	◯	◯	◯

Comments:

End-of-life Delphi Survey Round 2

*** 6. In Round 1, the MAJORITY (50%) AGREED with the following statement in relation to indicators of becoming more withdrawn in the EARLY PHASE:**

The resident has recently developed a faraway or vacant look.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 3.3%
Disagree 26.7%
Unsure 20.0%
Agree 43.3%
Strongly agree 6.7%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box.

In the EARLY PHASE an indicator of becoming more withdrawn is:

	Strongly Disagree	Disagree	Agree	Strongly Agree
The resident has recently developed a faraway or vacant look.	◯	◯	◯	◯

Comments:

End-of-life Delphi Survey Round 2

*** 7. In Round 1, the MAJORITY (53.1%) AGREED with the following statement in relation to the indicators of becoming more withdrawn in the EARLY PHASE:**

The resident has recently developed limited or no verbal interaction.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 0%
Disagree 28.1%
Unsure 18.8%
Agree 53.1%
Strongly agree 0%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box.

In the EARLY PHASE an indicator of becoming more withdrawn is:

	Strongly Disagree	Disagree	Agree	Strongly Agree
The resident has recently developed limited or no verbal interaction.	◯	◯	◯	◯

Comments:

*** 8. In Round 1, the MAJORITY (50%) DISAGREED with the following statement:**

To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, all three conditions of: recent decreased appetite, sudden increased frailty and recent acute withdrawal must be present.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 3.1%
Disagree 46.9%
Unsure 12.5%
Agree 37.5%
Strongly agree 0%

Please indicate your strength of agreement with the following statement by ticking the relevant box.

To confirm that the resident has entered the EARLY PHASE of change associated with the end-of-life phase, please indicate below all conditions which apply:

	Strongly Disagree	Disagree	Agree	Strongly Agree
Recent decreased appetite	◯	◯	◯	◯
Sudden increased frailty	◯	◯	◯	◯
Recent acute withdrawal	◯	◯	◯	◯

Comments:

*** 9. In Round 1, opinion was divided equally: 48.3% DISAGREED and 48.3% AGREED with the following statement:**

To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, all four conditions of: changes to the usual skin colour, poor peripheral circulation, changes to the usual breathing pattern and sudden increased pain on movement must be present.

The required consensus level of 75% was not achieved. The responses were:

Strongly disagree 0%
Disagree 48.3%
Unsure 3.4%
Agree 41.4%
Strongly agree 6.9%

Please indicate your strength of agreement with the following statement by ticking the relevant box.

To confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase, please indicate below all conditions which apply:

	Strongly Disagree	Disagree	Agree	Strongly Agree
Changes to the usual skin colour	◯	◯	◯	◯
Poor peripheral circulation	◯	◯	◯	◯
Changes to the usual breathing pattern	◯	◯	◯	◯
Sudden increased pain on movement	◯	◯	◯	◯

Comments:

5

6

3. Thank you

Thank you for participating in Round 2 of this Delphi survey.

When all responses have been received they will be analysed. The statements that achieve consensus in this round will be removed from the final round.

In the final round, you will be informed of the overall level of agreement with the statements in Round 2, and you will be asked whether you would like to conform to the majority view.

In this way, it is expected that most, but not necessarily all, statements will achieve consensus agreement.

End-of-life Delphi Survey Final Round

1. Welcome

Thank you very much for agreeing to participate in all of the rounds of this Delphi Survey. This is the 3rd and final round. As in Round 1 and 2, this survey comprises a series of statements about recognition of changes associated with the period prior to death of an elderly resident in a high level aged care facility.

The CLOSING DATE for this round is midnight 23rd June 2010.

As this is the final round of questions, the aim is to reach consensus agreement with each of the statements in the survey.

In Round 2, most statements achieved consensus, so these have been excluded from this round.

There were only three statements that did not reach consensus in Round 2. The purpose of Round 3, the final round, is to achieve consensus for these statements.

To help you make up your mind, the results from Round 2 are provided against each statement.

Round 3 should take less than 5 minutes to complete.

2. Round 3 Statements

This section contains generalised statements about residents with high level care needs. They may have been bed bound for some months and have slowly deteriorated during this time. These factors can make identification of the end-of-life phase difficult.

The Round 2 levels of agreement have been provided for each statement. The purpose of this is to help you decide whether or not to go with the majority view.

Each statement must be responded to prior to moving on to the next section of the survey.

End-of-life Delphi Survey Final Round

* **1. In Round 2, the MAJORITY DISAGREED (53.8%) with the following statement in relation to indicators of a decreased appetite in the EARLY PHASE or pre-terminal phase around two weeks before death:**

The resident has recently started to drool.

However the required consensus level of 75% was not achieved. The responses were:

Strongly disagree 0%
Disagree 58.3%
Agree 46.2%
Strongly agree 0%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box.

In the EARLY PHASE an indicator of a decreased appetite is:

	Disagree	Agree
The resident has recently started to drool.	◯	◯

Comments:

5

6

* **2. In Round 2, the MAJORITY AGREED that indicators of the EARLY PHASE of change associated with the end-of-life phase were Recent Decreased Appetite and Sudden Increased Frailty but were undecided with Recent Acute Withdrawal as the third indicator of the EARLY PHASE of change.**

However the required consensus level of 75% was not achieved.

The responses to Recent Acute Withdrawal as an indicator of a change associated with the EARLY PHASE were:

Strongly disagree 0%
Disagree 46.2%
Agree 53.8%
Strongly agree 0%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by ticking the relevant box:

	Disagree	Agree
An indicator which confirms that a resident has entered an EARLY PHASE of change associated with the end-of-life phase is Recent Acute	◯	◯

Withdrawal.

Comments:

* **3. In Round 2, the MAJORITY AGREED with the indicators which confirm that the resident has entered a LATER PHASE of change associated with the end-of-life phase are: changes to the usual skin colour, poor peripheral circulation and changes to the usual breathing pattern but were unsure about sudden increased pain on movement as the forth indicator of this phase.**

The required consensus level of 75% was not achieved.

The responses were to Sudden Increased Pain on Movement as an indicator of a change associated with the LATER PHASE were:

Strongly disagree 0%
Disagree 41.7%
Agree 58.3%
Strongly agree 0%

In the light of the above results, would you consider conforming to the majority view?

Please indicate your strength of agreement with the following statement by

ticking the relevant box.

	Disagree	Agree
An indicator which confirms that a resident has entered a LATER PHASE of change associated with the end-of-life phase is Sudden Increased Pain on Movement.	◯	◯

Comments:

3. Thank you

Thank you for participating in the final Round of this Delphi survey.

When all responses have been received they will be analysed and the results will provide a description of the end-of-life phase of care for elderly residents in high level care.

Your time and expert opinion in this research endeavour has been greatly appreciated.