

# **Gerotranscendence: A case study of the phenomenon of Advance Care Planning (ACP)**

**YEUN-SIM (SARAH) JEONG**  
**RN, MN, Grad Dip (Advanced Nursing), BNurs**

A thesis presented in fulfilment of the requirements  
for the degree of Doctor of Philosophy

**The University of Newcastle**  
**New South Wales**  
**Australia**

**November 2007**

*This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.*

(Signed) \_\_\_\_\_

**Yeun-Sim (Sarah) Jeong**

## **ACKNOWLEDGEMENTS**

This thesis would not have been completed without the encouragement, support and help of the people who have contributed to the study. First of all, I would like to give special thanks to the older people, their family members, and the nursing staff in the nursing homes where the study was conducted. In particular, my great appreciation is expressed to the CNC and the Directors of Nursing of the nursing homes for allowing me to conduct this study.

My sincere thanks go to Professor Mary FitzGerald who inspired me personally and professionally and led me in the right direction at the beginning of the study. I am most grateful to my principal supervisor, Professor Margaret McMillan, who kept the faith in me and believed in the value of the study. Her great support and constructive comments have been vitalising resources all the way through. I would also like to thank Doctor Isabel Higgins, my co-supervisor, for her critical and invaluable comments as well as her patience with editorial comments.

I gratefully acknowledge the scholarship and Early Career Researcher Grant provided by the University of Newcastle during the data collection and writing period.

Finally, and most of all, I am thankful to those who shared this journey with me for their endless patience, support, encouragement, and love: my husband Alister, my parents, my parents-in-law, my sisters and their families, and my dear friends.

# Table of Contents

Acknowledgment .....	iii
Table of Contents .....	iv
Key to Transcriptions .....	viii
Abbreviations.....	ix
Abstract.....	x

## Chapter One: Introduction

1.1 Background of the study.....	1
1.2 Definitions of Advance Care Planning (ACP) and Advance Care Directives (ACDs) ...	2
1.3 Two images.....	5
1.4 Significance of the study .....	9
1.5 The purpose and aims of the study.....	12
1.6 Research questions.....	12
1.7 Organisation of the thesis.....	13

## Chapter Two: Literature Review

Introduction .....	16
2.1 The emergence, prevalence and misuse of ACDs worldwide.....	18
2.2 ACP and ACDs in Australia.....	20
2.3 Legal aspects of ACP and ACDs in Australia .....	22
2.4 Benefits of ACP and use of ACDs.....	25
2.4.1 Practice of persons' autonomy.....	25
2.4.2 Communication and ACPs/ACDs .....	27
2.4.3 Cost-effectiveness .....	29
2.4.4 Directions from advance directives.....	30
2.5 When, why and how of ACP and ACDs in RACFs.....	32
2.6 The barriers to and predictors of ACP and ACDs .....	33
2.7 The roles of nurses in ACP and ACDs .....	36
2.8 Autonomy and clinical application of ACP .....	42
2.8.1 Autonomy in a social context .....	42
2.8.2 Autonomy in an era of economic rationalism .....	43
2.8.3 Autonomy within the context of standardisation .....	44
2.8.4 Autonomy without empowerment.....	45
Conclusion.....	47

## Chapter Three: Research Methodology

Introduction .....	50
3.1 Definitions of case-study research .....	50
3.2 History of case-study research.....	51
3.3 Case-study research in nursing.....	52
3.4 Advantages and disadvantages of case-study research .....	53
3.5 Validity and generalisability of case-study research .....	56
3.6 Rationale for the choice of case-study research and components.....	59
3.7 Case-study research design .....	62
3.8 Research setting.....	65
3.9 Data collection methods .....	65

3.9.1 Participant observation .....	67
3.9.2 Field notes.....	72
3.9.3 Document analysis.....	74
3.9.4 Semi-structured open-ended interview .....	76
3.9.4.1 Participant selection criteria for interview .....	77
3.9.4.2 Recruitment of the CNC.....	79
3.9.4.3 Recruitment of residents .....	80
3.9.4.4 Recruitment of family members.....	81
3.9.4.5 Recruitment of the RNs .....	83
3.9.4.6 Interview foci.....	85
3.10 Duty of care to participants and others.....	86
3.11 Ethical considerations .....	87
3.11.1 Informed consent .....	87
3.11.2 Voluntary participation .....	88
3.11.3 Protection of participants' privacy, confidentiality, and anonymity .....	89
3.12 Data analysis .....	90
Conclusion .....	96

## **Chapter Four: The Findings: Part One**

Introduction .....	97
Conceptual framework for research questions 1 and 2 .....	98
4.1 Input .....	104
4.1.1 Organisational policy and manual .....	104
4.1.2 Department of Health Guidelines.....	108
4.1.3 Psychological catalyst .....	110
4.1.4 Medical catalyst .....	111
4.1.5 The CNC.....	113
4.2 Throughput.....	114
4.2.1 Guardianship Board .....	115
4.2.2 Documentation .....	116
4.2.3 Case conference .....	124
4.2.4 Discussion.....	127
4.2.5 In-service education.....	130
4.2.6 Multidisciplinary consultation .....	132
4.2.7 Communication.....	135
4.2.8 Law and ethics .....	137
4.2.9 Timing of initiation.....	141
4.2.10 Obstacles/difficulties .....	147
4.3 Output .....	153
4.3.1 Documentation of ACD/POT.....	154
4.3.2 Autonomy for residents and clear directions for nursing staff.....	160
4.3.3 Person centred care (PCC) .....	162
4.3.4 Dying with dignity.....	165
4.3.5 Change of culture and attitudes toward discussing dying and death.....	166
Conclusion.....	169

## **Chapter Five: The Findings: Part Two**

Introduction .....	172
5.1 The experiences with ACP .....	173
5.1.1 Pre-transitional status .....	176
5.1.2 Transition .....	178
5.1.2.1 Enhancing factors .....	179
5.1.2.2 Inhibiting factors .....	192
5.1.3. Post-transitional status .....	197
In summary .....	201
5.2. The scope of nursing practice in ACP .....	203
5.2.1 The CNC .....	209
5.2.2 The DONs and RNs .....	219
Conclusion .....	233

## **Chapter Six: Discussion, Implications, Conclusion and The Montage**

Introduction .....	236
6.1 Discussion, implications and recommendations .....	237
6.1.1 Is ACP undertaken in a timely fashion? When should ACP begin? .....	237
6.1.2 How do we best capture what residents and families would want? .....	241
6.1.3 Four key determinative requisites .....	246
6.1.4 Autonomy in the social context .....	251
6.1.5 Change of culture and attitudes towards dying/death/ACP .....	253
6.1.6 Gerotranscendence by resident, families and the RNs .....	258
6.1.7 'Do it yourself' .....	260
6.1.8 Boundaries, discrepancies and a shift of responsibility in roles and functions .....	264
6.1.9 Lack of time, knowledge, skills, experience and confidence .....	265
6.1.10 Designating and delegating .....	266
6.2 Limitations of the study .....	268
6.3 Recommendations for further research .....	270
6.4 Conclusion and The Montage .....	274
Epilogue .....	284
<b>References .....</b>	<b>285</b>

## **Appendices .....305**

Appendix 1. Data collection: timeframe and processes .....	306
Appendix 2. Information letter for the DONs .....	307
Appendix 3. Permission to enter the premise of .....	310
Appendix 4. Announcement to non-participant residents and families in the facility .....	311
Appendix 5. Announcement to non-participant staff in the facility .....	313
Appendix 6. Information letter for the CNC .....	315
Appendix 7. Consent form for the CNC .....	319
Appendix 8. Preliminary work .....	320
Appendix 9. Information letter for residents and family members .....	321
Appendix 10. Consent for observation and interview .....	324



## Key to Transcriptions

The following abbreviations and conventions have been used throughout the thesis, where excerpts from the participants' transcriptions have been used.

Names: Pseudonyms are used to refer to participants. The only true name within the data is the researcher's.

[sic] indicates a word or phrase that may appear strange or incorrect has been written intentionally or has been quoted verbatim

... indicates a pause contained in the original material.

...//... material edited from the original for clarity

**Bold** indicates a word, phrase, or sentence relevant to theme(s) or narrative(s)



## Abbreviations

ACD	Advance Care Directives
ACP	Advance Care Planning
ADON	Assistant Director Of Nursing
A & E Department	Accident & Emergency Department
AHS	Area Health Service
AIN	Assistant In Nursing
CIT	Critical Incident Technique
CNC	Clinical Nurse Consultant
CPR	Cardiac Pulmonary Resuscitation
DM	Diabetes Mellitus
DON	Director of Nursing
DPOAHC	Durable Power of Attorney for Health Care
EG	Enduring Guardian
EPOA	Enduring Power of Attorney
FM	Family member
GDS	Geriatric Depression Scale
GP	General Practitioner
LW	Living Will
MND	Motor Neuron Disease
MMSE	Mini Mental Status Examination
MS	Multiple Sclerosis
NFR	Not for Resuscitation
NG	Naso-gastric
NSW	New South Wales
PACS	Post Acute Care Service
PCC	Person Centred Care
PEG	Percutaneous Endoscopic Gastric
POA	Power of Attorney
POT	Plan of Treatment
PR	Person Responsible
PSDA	Patient Self-determination Act
RACF	Residential Aged Care Facility
RCS	Resident Classification Scale
Res	Resident
RN	Registered Nurse

## **Abstract**

Current advanced medical technology allows people to survive longer than ever before, however, prolonged life may not necessarily equate to quality of life. Health-care professionals often have to face situations in which a patient is no longer able to make his/her own end-of-life care decisions. Consequently families are left in the uncomfortable position of wondering what the wishes of their loved ones may have been. Advance Care Planning (ACP), the focus of this study, is defined as the process of preparing for likely scenarios in end-of-life decision-making, which may or may not result in documenting an Advance Care Directive (ACD). An ACD is a statement made by a mentally competent person concerning how s/he wishes to be treated, if s/he loses mental capacity. The benefits of ACP are discussed in the literature and older people, especially in long-term care facilities, are considered as the best candidates for ACP, due to their multiple pathophysiological degenerative health breakdown with minimal chance of recovery. However, the available evidence suggests that the practices of ACP and the use of ACDs in particular in residential aged care are limited in Australia. The experience of people with ACP is only anecdotal.

This study was conducted to identify the implementation process of ACP by the Clinical Nurse Consultant (CNC) in Residential Aged Care Facilities (RACFs), to investigate the outcomes of ACP and experiences of people involved in ACP and ACDs, including residents, families, and nursing staff in RACFs, and to determine the extent of nursing participation and the scope of practice for nurses in the ACP process and the use of ACD.

Case-study research was chosen to enrich the understanding of the phenomena and to collect data in a natural setting using a range of data-collection methods. Data were collected through intensive participant observation over seven months, using field notes, semi-structured interviews with residents, family members, and RNs, and analysis of documents relevant to the study aims. Participants and three RACFs in NSW were selected because of their involvement in the ACP program.

The data collected from interviews and field notes were gathered and highlighted using critical incident technique (CIT) where it concerned behaviours, feelings, attitudes, opinions, comments, and perceptions in relation to each research question, for further

extensive thematic content analysis. The software program 'NVivo 7' was used to code and categorise large amounts of narrative text which were collected from open-ended interviews. The raw data to which the CIT and thematic content analysis were applied generated 50 narratives. Four major images created by these narratives in relation to each research question comprised the montage of the phenomenon of ACP in RACFs.

The research identified the conceptual framework which elaborated the elements in an 'Input, Throughput, and Output system' required for implementation of ACP. The study revealed that the residents', family members', and nurses' experience with ACP was positive as it promoted one's essence of being and autonomy. An understanding of the feelings, emotions, beliefs, and concerns of older people and their family members about ACP was achieved. The use of ACDs has confirmed that there are roles for nurses in the success of ACP and it has provided them with a new way to approach our ageing population in health-care decision-making for end-of-life care.

One area of the significant findings of this case-study research is that it captured how the older people themselves see and approach their explication of their own 'sense of self' and that of others in later life, and that they accept dying and death. The phenomenon of ACP is not limited to the end-of-life decision-making processes and/or documentation of treatment preferences at the end of life. Rather it expanded the extent to which nurses engage themselves with older people and their family members onto the level that is person centred and that enhances gerotranscendence through ACP. The current study of the phenomenon of ACP has made a contribution to greater awareness of what constitutes 'dying well' and how it can be achieved through 'A nursing theory of successful dying/gerotranscendence in end-of-life through ACP'. The study highlights the need to expand the domain of research to involve an exploration of experiences of 'successful dying'.

# Chapter 1

## Introduction

### 1.1 Background of the study

There is no argument that the world's population is ageing. In Australia, 13 per cent of the population were above the age of 65 in 2004 and the proportion of this population is projected to increase to 28 per cent by 2051 (Australian Bureau of Statistics, 2006). Increasing morbidity among older people, which is often associated with ageing, and increases in the use of technology have been the major contributors to relentless health-care costs with the ageing population. The ageing of the population has brought a number of challenges in policies, economics, the workforce and health-care services. Wade (2004) predicts that economic growth in 20 years will be halved, leaving governments with a \$2,200 billion budget hole over 40 years. Metherell (2004) warned that expensive life-saving treatments for older people will double the government spending on health over the next 40 years.

Increased health-care expenditure not only derives from the ageing population but also from the number of people with dementia. Dementia has been found to be the greatest single contributor to the cost of care in residential aged care (RAC) and to the burden of disease due to disability for older people. Alzheimer's disease is estimated to be responsible for 70 per cent of dementia cases in Australia, affecting 24 per cent of those aged 85 and over (Australian Institute of Health and Welfare (AIHW), 2004). Given that there are difficulties in identifying people with mild or moderate dementia, no definitive estimates of the number of people with dementia in Australia are available. However, it is estimated that two-thirds of those aged 80 years and over are affected by dementia (AIHW, 2004).

The implication of the increasing number of people with dementia is that dementia is accompanied by numerous health breakdown episodes which require medical treatments and eventuate in death. Health-care institutions, especially Residential Aged Care Facilities (RACFs), have increasingly become the site of death for older persons. Whilst the data on the

hospital or institution where the death occurred are not yet part of the National Health Data Dictionary in Australia, nursing homes and hospitals account for at least 54 per cent of all places of death in the United States of America (USA) (Gage & Dao, 2000). The majority of these deaths are preceded by a decision to forgo either cardio pulmonary resuscitation (CPR), other life-sustaining treatment, or hospitalisation (Teno, Branco et al., 1997). Approximately 70 per cent of deaths in hospitals involved a decision to withhold or limit medical intervention (Inman, 2002).

Another implication of the increasing numbers of people with dementia is that the majority of older people in RACFs lack the capacity to make decisions for themselves (Australian Government Department of Health and Ageing, 2003; Taylor & Cameron, 2002). Whilst Western society has fragmented experience around death and dying as something that happens to others and created a sense of alienation around end-of-life issues, it is important to note that most people with chronic degenerative diseases are faced with long and complicated processes of illness and become unable to make decisions for themselves (Mogg, 2006). At the end of life, most chronically ill older adults experience physical discomfort, limited mobility, and impaired cognitive functioning. Those who are mentally incapacitated and have not made plans for their own end-of-life care may receive either unwanted costly medical interventions or the withdrawal of wanted treatments (Lambert et al., 2005). Considering the financial and emotional costs associated with unwanted, unnecessary or contested medical treatments at the end of life, growing attention has been paid in recent years to the concept of Advance Care Planning (ACP) and Advance Care Directives (ACDs).

## **1.2 Definitions of Advance Care Planning (ACP) and Advance Care Directives (ACDs)**

Advance Planning (AP), Advance Medical Planning (AMP), Advance Care Directives (ACDs), Advance Health Directives (AHDs), Advance Medical Directives (AMDs), Advance Care Planning (ACP) and Advance Directives (ADs) appear to describe the need to make decisions for the 'end-of-life' care in the literature. For the purpose of this study, the researcher has used ACP and ACDs, as these are the terms used in the Australian health-care context.

As the focal point of the research project derives from ‘end of life’, it is imperative to define what is meant by ‘end of life’. Steihauser et al. (2000) identified that there was a considerable variation in definition of ‘terminal’ and ‘end of life’, ranging from less than four weeks to more than 36 weeks of life remaining. The researcher is uneasy with this narrow timeframe, given that ‘end of life’ may not necessarily be incurred in an experience of a terminal illness but may be less predictable or may take longer, due to the progressive nature of the illness. For the purpose of this study, ‘end of life’ partly adapts the definition from Field and Cassel (1997) and implies the concluding phase of a life when one comes to a realisation of ‘approaching death’ and ‘ending in death’, with varying levels of intimacy and openness with families, friends, and health-care givers. This means that the timeframe with narrow duration for end of life is not significant in this study as much as it is in the literature. It means that an individual defines end of life when s/he feels that her or his life is close to concluding and that s/he engages her or himself in the process to accept the conclusion of life, and when one shares this feeling and process with others. This embraces the fact that older people do think about either the death of their close friends, loved ones or their own death, although they do not feel the imminence of their own death, and the profoundly personal nature of dying is unrecognised by health-care systems (Byock, 1996; Kring, 2006).

Advance Health Directives (AHDs), first proposed by Kutner in 1967 (Hong & Lee, 1996), are written statements to express individuals’ plan for themselves if they become incapable of making decisions (Blondeau et al., 1998). Since then the concept of AHDs was adopted by the US government in 1991 as Advance Directives (ADs) in an endeavour to represent individuals’ wishes in regard to health-care decisions for themselves at the end of life. ACDs are defined as “statements made either made orally or in writing by a mentally competent adult stating how they wish to be treated should they, at some stage in the future, lose mental capacity” (Biegler et al., 2000; Stewart & Bowker, 1998, p. 151). The most common forms of written ACDs in US are a living will (LW) and the appointment of a health-care agent, commonly called a durable power of attorney for health care (DPAHC) (Havens, 2000). A ‘living will’ gives specific directions concerning health care and appoints an agent or proxy to make decisions in the case of a terminal illness. The DPAHC authorises an agent or surrogate to make health-

care decisions on behalf of an individual in the event that the patient is incapacitated (Havens, 2000; Kirmse, 1998). Ultimately, an ACD is intended to make an individual's personal health-care choices clear to family, friends and health-care providers and ensure that the treatment received is agreeable with his or her personal preferences and values (Kirmse, 1998). Therefore, unlike other autonomous actions in which they engage, individuals depend on others to carry out the choices they convey in their executed ACDs (Havens, 2000).

Ideally, the completion of ACDs culminates in conversations individuals have with family members, surrogates, close friends, and health-care professionals about the kind of care they wish at the end of their life (Havens 2000). However, the literature reveals the massive emphasis on how to increase the completion rate of ACDs and it did not necessarily achieve the original intentions of the ACDs. Extensive efforts towards the completion rate of ACDs among seriously ill patients have been criticised because of a heavy focus on the reduction in the use of resources (Teno et al., 1994; Teno et al., 1995).

The institutionalisation of ACDs has occurred without empirical evidence demonstrating that ACDs have achieved their goals (Fagerlin et al., 2002). Given that ACDs are simply statements, they failed to embrace the importance of the discussion process between patient and health professionals, the need for family involvement, and follow-up processes after the completion of ACDs. According to Norlander and McSteen (2000), when one needs to make decisions about the end of life, experiences for an individual and the process should be a thoughtful and facilitated discussion that encompasses a discussion about a lifetime of values, beliefs, and goals for the patient and family. For this reason, ACP was introduced and embraced by health-care professionals (Jordens et al., 2005). Advance Care Planning (ACP), the focus of this case study, is defined as:

the process of preparing for likely scenarios near the end of life that usually includes assessment of, and dialogue about, a person's understanding of their medical history and condition, values, preferences, and personal and family resources

(NSW Health Guidelines, 2004, p. 1).

Public Advocate Julian Gardner in the state of Victoria in Australia emphasised that ACP enables patients to reflect on what is important to them – their beliefs, values, goals and preferences in life – and how they wish to be cared for should they reach a point at which they cannot communicate decisions about their medical care (Mogg, 2006).

There are two main elements in ACP; the written ACDs and the appointment of a substitute decision-maker. Completion of ACDs should merely be one component of the broader ACP process. Appointment of an ‘enduring guardian’ who acts as an individual’s substitute decision-maker is the second component that is endorsed by The *Guardianship Act 1987* in New South Wales (NSW), Australia (NSW, 2004). However, it is necessary to clarify some of the terms used, as members of the public believe that a Power of Attorney (POA) can make medical decisions for them (Mador, 2001). A POA in NSW is the person appointed to look after assets and financial affairs and is automatically cancelled if the person who gave the power becomes of unsound mind – that is, becomes legally incapacitated. Enduring Power of Attorney (EPOA) gives another person (or persons) – nominated by an individual – the legal power to act on his/her behalf in relation to assets and financial affairs while the individual is still living. It remains legally in force even if the person who gave the power becomes of unsound mind – that is, becomes legally incapacitated (Nation Wise Products, 2002).

In NSW, individuals need to be clear that the person appointed as their attorney under an EPOA is allowed to make decisions about assets and financial affairs but not about medical treatment. The law in NSW, Australia, permits a person appointed only as ‘Enduring Guardian (EG)’ to make decisions about medical treatment – although the law does not give the enduring guardian the authority to override objections to medical treatment. Only the Guardianship Tribunal can do this (Nation Wise Products, 2002). It is important to note that legislation governing issues surrounding decision making varies in each state and territory in Australia (Beigler et al., 2000; Cartwright, 2000).



### 1.3 Two images

Contemporary health care supported by advanced medical technology allows people to survive longer than ever before, however, prolonging life does not necessarily improve the quality of life. Health-care professionals often face situations in which a patient is no longer able to make his/her own end-of-life care decisions and their families are left in the uncomfortable position of wondering what their loved one's wishes may have been. The researcher presents two images that were experienced by her and that culminated in a need to explore the issues in relation to end-of-life care decision-making. The two images provide readers with experiences and dilemmas that relatives and nurses have encountered with patients who were dying, who had not made their end-of-life wishes known or who had not had the opportunity to make the wishes known. The two images signify the issues related to end-of-life care decision-making raised in the background of the study and stimulate interest to proceed to identify the significance of the study.

#### *Image One*

*Mr Cho was lying helplessly in his bed in a cardiovascular special ward. It was the eighth admission over the last twelve months for end-stage congestive heart failure. His first-born son was in vigil at his bedside and seemed to accept his father's death in the near future. Mr Cho had had his 86<sup>th</sup> birthday two months ago with his two sons and two daughters around him at home. He made it clear that he was ready to go and reunite with his wife who had passed away seven years ago as a result of stomach cancer. He was resuscitated from a cardiac arrest in a previous admission at his first son's request. The first son told the doctors on this admission not to resuscitate him if he had another heart attack.*

*One morning, Mr Cho was found unconscious by his second son who pressed the red buzzer. The second son shouted at the nurses to save his father. The nurses on duty alerted the doctors and all of sudden Mr Cho was surrounded by three doctors and three nurses who were on a mission to resuscitate him. Mr Cho was intubated and had cardiac defibrillator shock twice but was still not responsive. Then the first son walked into the room, yelling at the doctors and nurses to stop doing what they were doing. The first son*

*brought everyone to a standstill with his loud voice and outcry not to resuscitate his father and to leave him in peace. The doctors and nurses stopped resuscitation and looked at the second son. The second son started yelling at his brother, accusing him of killing the father. Aggressive arguments took place between the two sons at that time over whether to resuscitate their father or not. The second son threatened to sue the medical team for negligence. So the doctors resumed resuscitation. And then the first son spoke calmly that he was the one who was legally responsible for making decisions, which was true, and would take all the responsibility for letting his father go now. The first son blamed his brother for the senseless request to satisfy his greed, as the second son wanted his father alive to change the will in order to inherit more money than what was promised at this time. So the doctors and the nurses stopped resuscitation. It was a cruel, ugly, and inhumane situation. I was one of the nurses. I was only a new graduate nurse who was very confused, somewhat bitter, cynical, puzzled, sad, sympathetic and compassionate all at the same time. This episode has stuck in the back of my mind since then and there were a number of similar stories like this one in my 20- year nursing career.*

## *Image Two*

*George, who was 63 years old, became hemiplegic following a stroke two and a half years earlier. He has been living in a nursing home since then. His speech was severely affected so he could only groan and grimace when something was not right for him. No one could understand even a word from him. He was bed-bound and required two staff as assistance for activities of daily living (ADLs). He was on a Kangaroo pump for continuous Percutaneous Endoscopic Gastrostomy (PEG) tube feeding with a strict regime, as he could not digest more than 60 ml per hour. The only visitor he had was a lady called 'Cheryl'. Cheryl, who was in her 60s, insisted that she had been just his neighbour for 10 years and refused to be his guardian. Cheryl informed the staff that George might have an estranged son in France but she did not know anything more than that. George never smiled or expressed his emotions. He would spend most of the time looking at the ceiling or window blankly. He would not respond to the staff who changed his fluid bag on the PEG tube but kept looking at the tube and the face of the staff in turn. He did not interact with Cheryl either, when she visited once a week. It was not known if he knew who she was and what was happening around him. What was surprising though, was that he would*

*clench his fist and tried to sway it in the air when he was frustrated. He would groan when he was wet with urine or faeces.*

*A staff member found dark-brown-coloured faeces on his pad one morning. The doctor was notified but nothing was done. George was febrile and agitated three days later. He was aggressive to the staff member who was changing his pad. The staff member found his pad was soiled with brown faeces again. George started vomiting brown stuff through his mouth two hours later. The doctor was notified and he was sent to the Accident and Emergency (A & E) Department in hospital at 9.00 p.m. George came back to the nursing home at 10.00 a.m. next day. George was given Panadol for his fever and an x-ray of his abdomen presented nothing significant. The staff member in the nursing home was informed that George did not show any signs of bleeding and was not febrile, so he was returned to the nursing home. George seemed to be exhausted and lost. The staff member made sure that he was comfortable in his bed with minimal interruption for the rest of the day.*

*A staff member found that George had a flushed red face at about 4.00 p.m. two days after he came back from the hospital. He had fever of 37.8 °C. He was given Panadol through his PEG tube at 4.20 p.m. His temperature was 37.5 °C at 5.30 p.m. and he had brown-coloured vomiting at 7.00 p.m. His feeding through PEG tube was stopped immediately. The doctor was notified and the staff member was asked to observe him closely. George did not look well and kept his eyes closed. The staff member noticed that he was a bit dehydrated and seemed to be weak. His temperature was 37.3 °C at 8.00 p.m. The doctor was notified and George was sent to the hospital again at 9.20 p.m. The staff at the nursing home received a call from the A & E Department at the hospital that George would be sent back to the nursing home, as his symptoms were subsiding. George was given Intra-venous (IV) drips for dehydration. He was also given morphine as he was aggressive and agitated. George was back in his bed at 4.00 p.m. next day. The staff found a pressure sore the size of 1.5 x 1.8 cm on his sacrum when he was transferred from the trolley to his bed. The staff at the nursing home were frustrated and felt helpless about what had been done and what had not been done to George in the hospital.*

*George was sent to the hospital and back to the nursing home three more times in another week. The whole nursing home was talking about George. Some staff blamed George for*

*smoking since he was 16. Some staff made the assumption that he would not have been a good father or husband and he was responsible for what he was going through now. The staff members were curious about the mysterious part of his past life, the unknown wife, his estranged son, and Cheryl. Some staff believed that George deserved better care than what he was getting now, no matter who or what he was in the past. The staff wondered what the current George would say to them about what to do if he was able. They were frustrated about whether the hospital could do more about the brown vomitus and faeces than what had been done. They were resentful that the trips to the hospital were doing more harm than good to George. There were so many speculations about George and his care needs that the staff could not stop talking about it. However, there was consensus on one point: that no one would like to be in George's situation. Everyone seemed to agree that no one should go through what George was going through. I was one of them. I was stuck with the questions: 'How could we find out what George would have wanted?', 'Why were we doing things to George that we would not want for ourselves or our loved ones?', 'Was there anything we could do to make a difference?', and 'What would I want to see happening to George and many other residents in the nursing home?' I was mystified by what was happening to George and asking why. I was also horrified by how many residents go through what George went through. I felt helpless, as I did not know what to do to help them, myself and other nurses enquiring about it.*

#### **1.4 Significance of the study**

Along with the images described above, increased awareness and interest by the general population in end-of-life decision-making is evident in the responses shown in the following two terminally ill patients with no hope of recovery. Terri Schiavo, who was a healthy young American woman with her life ahead of her, suffered a brain injury and remained in a 'persistent vegetative state' for 15 years. Maria Korp in Australia was violently assaulted and bound in the boot of a car for several days before she was discovered, severely dehydrated but alive. Like Terri Schiavo, Maria Korp did not regain consciousness and, according to medical experts, was not likely ever to do so (Skene, 2005). Australians' interest in those two cases represents an increasing awareness and demand for lawful and ethical ways of end-of-life decision-making processes.

Whilst the use of ACD is widely accepted in principle in North America and the United Kingdom (Waddell et al., 1996), Australia has been slow to address this area to date. Until very recently the practice of ACP and ACDs was rarely discussed in Australia (Taylor & Cameron, 2002; Waddell et al., 1996). The available evidence on the prevalence of ACDs in Australia suggests that ACP in this country has been poorly implemented and that many patients may remain disempowered with regard to their end-of-life medical management (Duffield, 1998; Hawkins & Cartwright, 2000; Kirmse, 1998; Taylor & Cameron, 2002). Taylor and Cameron (2002) focused on older people who present to Emergency Departments in Australian hospitals. Older people typically have multiple pathophysiology underlying their medical problems that may lead to decision-making to forgo either CPR, other life-sustaining treatment, or hospitalisation. However, these older people are rarely consulted about ACDs to guide the management of their care. When older people are unable to communicate, health-care professionals and family members are left to wonder about the extent of invasive management that the older patient might desire.

The Respecting Patient Choices (RPC) program, first introduced in 2002 at the Austin Hospital in Victoria, Australia, aimed to help patients and their families in end-of-life care decision-making (Mogg, 2006). The initiation of ACP in the Australian context was welcome and appreciated, as it responded to the growing need to address the issues related to end-of-life care decision-making. However, the program was based on an American model developed at the Gundersen Lutheran Medical Foundation (Mogg, 2006; Seal, 2007; Shanley & Wall, 2004) and, as a result, the program needed to be adapted to address the absence of legislation in relation to ACDs and the multicultural composition of the Australian community. The program was piloted in 10 wards at the Austin hospital and was introduced to patients who were competent. Unfortunately, scientific evidence from a formal investigation of how the RPC program was implemented and accepted by the participants of the program was not available at the time of the commencement of the current study.

The RACF that comprises low level care what was formally referred to as hostel accommodation and high level care known as nursing home in Australia, will be the place of care and site of death for growing numbers of frail, older persons dying of chronic progressive

illnesses (Wowchuk, McClement & Bond Jr, 2006) and provides a unique opportunity to investigate the nature and extent of the use of ACP with residents and their families. The increasing complexity of medicine, the greater capacity for medical intervention to maintain life, the apparent increase in levels of interest by the older people to participate in decision-making and the high prevalence of incompetence in decision-making among nursing home residents, are all issues that support an argument for greater exploration of the process of ACP in long-term care (Nair et al., 2000).

ACP and the use of ACDs appear to offer a significant role for nurses because of their close connection with patients and family members, their philosophical commitment to patient autonomy, and their intimate involvement in providing end-of-life care (Haynor, 1998; Jacobson, 2000; Shanley & Wall, 2004). In RACFs, where many deaths occur, the involvement of the medical practitioner may be minimal and the nurse may well be the key point of contact for the resident. However, over a decade ago there was virtually no acknowledgment of the major roles which nurses play in ACP and ACDs (Chiarella, 1994). The Australian Nursing and Midwifery Council Incorporated (ANMCI) sees the nurse's role as including the provision of assistance to the dying by helping patients record their end-of-life care treatment wishes and to help them achieve a dignified death (Cartwright et al., 1997). There was some literature that supported the nurse's role as patient advocate in discussing ACDs with patients, ensuring that patients are informed of their rights and that decisions are known to the healthcare team and respected by them (Crego & Lipp 1998; Ott 1999; Shanley & Wall, 2004).

Formal designations that focus on the management and promulgation of ACPs are also limited. The only experienced nurse clinician in NSW, Australia who specifically focuses on the implementation and management of ACPs and ACDs for older people holds a Clinical Nurse Consultant (CNC) position in a metropolitan Area Health Service. Her role requires her to work from the health service perspective and promote ACP in residential aged care settings. The ACP program and the use of ACDs in RACFs in which the CNC was involved were initiated as a part of the Chronic & Complex Care Program Project in NSW, Australia in 2001. However, the published research regarding ACP and ACDs in Australia is scant and the existence of relatively few research articles by nurses suggest that nurses are not heavily

involved in ACP and research regarding ACDs.

In summary, the process that leads to end-of-life decision-making and action in clinical practice is not well developed in residential aged care. Furthermore, the factors that determine who ultimately makes a treatment decision, what influences treatment choice, and how the treatment is carried out have yet to be established (Waddell et al., 1996). Lack of discussion and information on this topic has prevented the individual and/or family members from having a chance to retain their autonomy and authority as decision-makers in situations in where they are no longer able to provide input (Duffield, 1998; Hawkins & Cartwright, 2000; Kirmse, 1998). Limited discussion may also impede the acceptance of a role in ACP by nurses in the RACFs, thereby disadvantaging residents who would like to express their views in advance of possible incompetence in decision-making preceding death. Hence, the ACP debate should be evidence-based and relevant to the findings of research undertaken in this country.

### **1.5 The purpose and aims of the study**

The purpose of the study was to investigate the phenomenon of ACP in RACFs in the Australian context. The aims of the study were to:

- investigate the implementation process of ACP and the use of ACDs by the CNC in RACFs
- investigate the outcomes of ACP and experiences of people involved in ACP and ACDs, including residents, families, and nursing staff in RACFs
- determine the extent of nursing participation and the scope of practice for nurses in ACP process and the use of ACD.

### **1.6 Research Questions**

The research questions are:

1. How and why are ACP and the use of ACDs implemented by the CNC in RACFs?
2. What are the outcomes of ACP on residents, family members and RNs?
3. How do residents, family members and RNs perceive their experience with ACP in RACFs?
4. How is the scope of practice perceived by the CNC and RNs in ACP in RACFs?

### 1.7 Organisation of the thesis

This thesis consists of six chapters. **Chapter One** has outlined the background, significance, purpose and aims of the study. The definitions of ACP and ACDs are provided and have established a basic understanding for more in depth discussion. The two images captured within the experiences of the researcher throughout her nursing career were presented to draw attention to the issues of end-of-life decision-making in health-care settings. The issues which emerged in the images were the extent to which one could refuse treatment; whether the expressed wishes of refusal of treatment would be respected by others; given that one could not speak for him/herself who was responsible for making end-of-life care decisions; on what basis decisions were made; what the consequences of the decisions made are; what the legal ramifications of the decisions made by a substitute decision-maker are; and what role health-care professionals should perform in health-care decision-making. The images presented are derived from personal perceptions and recollection, but the issues projected by the images represent concerns of many others in the literature, which are discussed in the literature review.

The literature review in **Chapter Two** details when ACP emerged and how it developed worldwide. ACP and ACDs are endorsed for various reasons, hence the benefits and positive outcomes of ACP and written directives are discussed. Decisions about when and in which health-care settings ACP should be initiated were slow to emerge, despite strong justification for the implementation of ACP in RACFs in the literature. The literature reports the difficulties experienced by health-care professionals in the ACP process and the use of ACDs. Those difficulties have challenged the nurses in their roles and functions in ACP. The literature



review reveals that the participation and contribution of nurses in the end-of-life care decision-making process is lacking serious debate, due to the absence of scientific evidence. The chapter concludes by reiterating the aims and directions of the study.

The research design and methods used to investigate the phenomenon of ACP in RACFs are described in **Chapter Three**. The case study as a research method is explored by discussing the definition of case study, the application of the case study in nursing research, the strengths and weaknesses of the case-study research methodology. The case-study research method chosen for current research is justified. Data-collection methods, which include participant observation, semi-structured interviews, and document analysis are presented in order to provide detailed descriptions of a rigorous and scientific approach to investigate the phenomenon of ACP. The data collected were analysed using the Critical Incident Technique (CIT), which resulted in a number of narratives to capture all the images in relation to ACP in RACFs.

**In Chapter Four**, the findings related to the research questions 1 and 2 are presented. The conceptual framework adopted and modified from the work of Axford (Axford, 1995) to present the implementation process of ACP (research question 1) and the outcomes of ACP (research question 2) is described. Narratives are used to provide full descriptions of ACP processes and outcomes. The processes and outcomes of ACP are captured in three elements, which are inputs, throughputs, and outputs, and 20 sub-elements in the conceptual framework (see Figure 4 – 1). The implementation process required five essential inputs as resources to initiate ACP. Ten sub-elements in throughputs that nurses needed to work with/through in the process of ACP and the completion of directives are identified and described. Five sub-elements in the outputs of ACP are revealed in residents', families', and RNs' comments.

**Chapter Five** is presented in two sections. The findings provide nursing professionals with missing parts in understanding the phenomenon of ACP. The first section answers research question 3 on the experiences of residents, families and RNs with ACP and ACDs. The narratives provided by the participants depict rich and unique knowledge of their experiences with ACP in RACFs. On the one hand, the residents' stories and their experiences were distinctive from the family members' and nurses', but on the other hand they shared similar

emotions, feelings and concerns with each other. Section two presents the scope of nursing practice for the expert nurse and the RNs in ACP in RACFs. Two models developed to describe the scope of nursing practice in ACP provide the RNs with directions for the future, as they were challenged and they desired to expand their roles and functions in end-of-life care decision-making processes.

In **Chapter Six**, the findings of the study are discussed further in order to extend the level of understanding of the phenomenon of ACP in RACFs and to identify implications for nurses and the nursing profession. The discussions and implications are drawn together in relation to each research question. Theoretical and philosophical underpinnings were sought from the relevant literature in order to increase the meanings of the narratives and the depth of the discussions. Recommendations for nurses and nursing practice are included in order to prompt changes in practice with regard to end-of-life care in RACFs and to help nurses be better prepared for upcoming demands in ACP for the ageing population. This final chapter concludes with the montages to describe an enlightening final discovery from the investigation of the phenomenon of ACP in RACFs.

The following chapter provides a comprehensive and extensive review of the literature in relation to ACP and ACDs. The phenomenon of ACP is obvious and the demand for ACDs from health-care professionals is strong. It cannot be denied by nurses and the nursing profession that they need to accept the professional responsibility and to become active participants in end-of-life care decision-making.

## Chapter 2

### Literature Review

#### Introduction

In this chapter, the literature in relation to ACP and ACDs is critically reviewed. A critical review of studies is drawn from various disciplines: psychology, sociology, medicine, nursing and allied health. The concepts of ACP and ACDs are explored, together with its origins. Then the depth and width of the review are expanded to a global perspective, with specific attention given to the Australian health-care context where literature was available. The review of literature was conducted to generate a picture of the existing body of knowledge in order to promote a basic understanding about ACP and ACDs. It was an attempt to identify and analyse the underlying issues with ACP and ACDs and yielded discussion on the applicability, accessibility and relevance to the nurses and contemporary nursing practice. The gaps identified between the countries in worldwide, current practice of ACP and future demand for ACP in Australia, and participation by nurses in contemporary and future nursing practice are discussed. This eventually assisted the researcher with developing the research questions and designing the research project. The themes categorised from the literature review are as follows: the emergence and prevalence of ACDs worldwide; ACP & ACDs in Australia; legal aspects of ACP and ACDs in Australia; benefits/positive outcomes of ACP; the when, why and how of the emergence of ACP and ACDs in RACFs; the barriers to and predictors of ACP and ACDs; the roles of nurses in ACP and ACDs; autonomy and clinical application of ACP.

#### 2.1 The emergence, prevalence, and misuse of ACDs worldwide

The case that provided an incentive to discuss ACDs was Nancy Cruzan, who was born in 1957 and was in a persistent vegetative state for seven years after a car accident in 1983. In 1987, her parents asked to have Cruzan's feeding tube removed, but the hospital demanded a court order to that effect. Her family fought in courts for three years and the trial went to the Supreme Court where it was ruled that artificial nutrition and hydration could not be withdrawn from a patient in a persistent vegetative state who was not terminally ill, unless there was proof that she had authorised such termination. The Cruzans lost the battle but

the family ultimately prevailed by providing additional evidence. On December 14, 1990, the tube was removed and she died 12 days later (Kirmse, 1998).

Nancy was a figure in the right-to-die movement. To encourage members of the public to be proactive about expressing their end-of-life treatment wishes, including the execution of ACDs, a statutory basis has been established in all 50 states, under the *Patient Self-Determination Act (PSDA)*, to encourage the use of ACD. The Act stipulates that anyone entering a health-care facility, such as a hospital or nursing home, must be asked if he/she has an ACD (Inman, 2002; Taylor & Cameron, 2002). The PSDA, implemented on December, 1, 1991 enacted in response to the Cruzan 'right-to-die' case, requires all health-care facilities receiving Medicare and Medicaid reimbursement to provide written information to individuals at the time of admission or of enrolment concerning their rights under state law to make decisions about health care, including the right to execute ACDs (Ball, 2006; Havens, 2000; Haynor, 1998; Teno et al., 1997). This law also requires recognition of the Living Will and Durable Power of Attorney for Health Care (DPAHC) (or health care proxy) as ACDs. The Act also directs the provider or organisation to provide staff and community education on issues concerning ACDs (Havens, 2000; Haynor, 1998).

Since then, a variety of factors have contributed to increased interest in end-of-life care decisions. Among these are rapidly increasing health-care costs (Chochinov & Janson, 1998; Crego & Lipp, 1998; Folbrecht, 1997), the ageing population (Cartwright, 2000; Chochinov & Janson, 1998; Mezey, Bottrell, & Ramsey, 1996), new life-sustaining technologies (Cartwright, 2000; Crego & Lipp, 1998; Meyer, 2000), increasing patient awareness and demands for autonomy (Cartwright, 2000; Inman, 2002; Johns, 1996; Perrin, 1997), the increasing numbers of older people who do not have a relative or friend who can make care decisions for them (Mezey, Bottrell, & Ramsey, 1996), and increasing litigation associated with health care (Chochinov & Janson, 1998).

Unfortunately, despite the 1991 PSDA in America to legally implement ACDs and the above factors, available evidence does indicate that the completion rates are low and does not indicate an increase in the rate of execution of ACDs in the USA (Havens, 2000). Multiple studies show the rate varies from 0 per cent to 26 per cent in the general population, 5–20 per cent in nursing homes, and 56 per cent in the seriously ill (Hahn,

2003; Kirmse, 1998; Murphy, Sweeney & Chiriboga, 2000; Palker & Nettles-Carlson 1995; Perrin 1997). Havens (2000) conducted a study to investigate the rate of ACD execution among Vermont community-dwelling adults in America. Eighteen per cent out of 210 respondents had executed an ACD. In other studies, ACD execution rates among community-dwelling adults range from 17 per cent (Mansell et al., 1999) to 33 per cent (Gordon & Shade, 1999) with intervention to increase the documentation rate.

The majority of Americans have not written an ACD and health-care institutions have rarely collected information about directives even when they are completed (Carr & Khodyakov, 2007; Teno, Branco et al., 1997). ACDs, since they were introduced by law in the USA have received numerous criticism as their meaning has drifted away from the original concept. Many have debated the appropriateness of the timing of admission to inform patients about advance care directives, the lack of obligations imposed on physicians, and the cost of implementing the PSDA (Teno, Branco et al., 1997).

Limited interpretation and implementation of ACDs has also added to the failure to promote ACDs. For example, people make decisions throughout life based on our experiences, values, goals, and sociocultural norms. Making decisions about how we would like to be treated at the end of life is no different (Norlander & McSteen, 2000). Pearlman et al. (1995 cited in Norlander & McSteen, 2000) claimed that

It (ACP) is intended to maximise beneficial medical treatment decisions in the event of mental incapacitation, promote shared understanding of relevant values and preferences between the patient and both her health care providers and family members, reduce burden on and conflict with family members at the time of future decision-making, and avoid errors of overtreatment and undertreatment when patients can no longer indicate for themselves what they consider to be worthwhile treatment (p. 359).

It is clearly stated that ACP aims to avoid both overtreatment and undertreatment. Increasingly, however, ACP has been often viewed as a tool to limit care. For example, a study of the effects of ACDs on medical treatments and costs was performed (Levinsky, 1996). ACP for patients when they are well can set forth general principles to guide their care in the later stages of life. However, the care of the seriously ill patient is complex. The thought and decision-making processes of very sick patients are often distorted by the emotional pressures and physical problems of acute illness (Levinsky, 1996).

Another example of common misunderstanding about ACDs is that people believe that it is only about a Do-Not-Resuscitate (DNR) order. A number of studies that discussed end-of-life decision-making only and heavily focused on the DNR order and medical futility. For example, Dunlap (1997) emphasised that medical futility is the ‘when’ of ACD implementation. This generates the view that the ACD execution is equal to death or the DNR order. It was argued that if ACDs are to be considered more as a true meaning of communication channel at the end of life, various issues have to be discussed. There could be cases in which an individual wants to be resuscitated even though medical professionals point out that the treatment would be futile. If the individual’s wishes are to be accomplished whether it is futile or not, something has to be written by the individual. This biased attitude leads the public in the wrong direction, whereby they believe that ACP should be implemented at the end of life and that there will be undertreatment when they participate in ACP and complete ACDs.

Even though the discussion of ACDs derived from an incapacitated patient in a hospital setting, the *Patient Self-Determination Act* included long-term facilities to recognise and honour residents’ written ACDs (Teno, Branco et al., 1997). However, it was implemented in the face of limited research about advance care planning in long-term care facilities (Fagerlin et al., 2002). With the absence of preparation for the fact that the majority of residents in long-term care facilities lacked the capacity to make decisions for themselves (Allen et al., 2003), low rates of documentation of ACDs in nursing homes were not surprising. Allen and her colleagues also found that the Mini Mental Status Examination (MMSE) was a commonly used tool to assess capacity of an old person to make decisions, although its usefulness to measure understanding the treatment situation is limited. Proxies’ attributes and needs to facilitate plan for the end of life were not well reflected in ACP in nursing homes, where often the proxy was the one who held a key position to initiate and participate in the planning.

‘Advance statements’ as a mean to enhance personal autonomy and to protect the rights of dying persons in the United Kingdom (UK) have been a central issue in end-of-life deliberations but more contested, although they have acquired undisputed legal status in the USA and Canada (Seymour et al., 2004). They are now recognised to have legal force under common law in the UK, although there is no statute regarding advance statements (Kessel & Meran, 1998; Travis et al., 2001). This ‘common-law’ position on advance

refusals of treatment has become enshrined in statute, and a new role of Lasting Power of Attorney (LPA) for welfare, including health care, has been created (Department of Health, 2005; Thompson, Barbour & Schwartz, 2003). In the UK, only a quarter of older people had discussed end-of-life health care with those they would nominate as their LPA for health care (Schiff, Rajkumar & Bulpitt, 2000).

The issues in relation to advance directives in the USA are also experienced in the UK and other European countries. Increasing numbers of patients who are unconscious or cognitively impaired are dying in hospital settings. However, in practice, ACP is rarely used. End-of-life decisions are often made by mostly physicians or families (Fassier et al., 2005). Regulations for ACP are changing in many European countries. In the last decade, advance directives were acknowledged as legally valid in Belgium (2002), Denmark (1998), France (2004), Germany, The Netherlands, Spain (2002), the UK and Switzerland (French Senate, 2004). Fassier et al. (2005) noted that paternalism is clearly no longer the rule in Europe, although European physicians are often described as paternalistic. Communication with families is encouraged as a means of empowering families in end-of-life care decision-making.

The principle of the advance directive was introduced in the last twenty-five years in the USA and during the last decade in the UK. Hence, it is not surprising that the majority of literature with regard to older people and end-of-life planning comes from North America. Seymour et al. (2004) argued that there was little empirical research in the UK and identified the neglected perspectives on the issues: (a) the extent to which advance statements are perceived by the public to be useful for protecting individual autonomy, (b) what issues are perceived to be associated with the process of their development and with their use in end-of-life care, (c) the views of older people, and (d) whether the emphasis on autonomy resonates with lay understandings of how dying people should be cared for by their families and clinicians.

## **2.2 ACP and ACDs in Australia**

Notably, many of the issues pertaining to ACD that have been investigated overseas have, thus far, largely not been investigated in this country. Waddell et al. (1996) argued that the use of advance care planning is accepted in principle in North America and the UK.

However, the practice is rarely even discussed in Australia. Taylor and Cameron (2002) noted that the older people who present to emergency departments in the Australian context have multiple pathophysiology, with life-sustaining appliances including percutaneous feeding tubes, permanent urinary catheters and internal defibrillation devices fitted. These people rarely present with ACDs to guide management, and one may wonder about the extent of management that the patient would desire, if this could be effectively communicated.

ACP discussion rates in Australia are generally low and vary widely, ranging from less than 1 per cent to 29 per cent (Hawkins & Cartwright, 2000; Kerridge et al., 1998; Ryan, 1996). For example, Hawkins and Cartwright (2000) revealed 5 per cent prevalence in one general practice in Queensland. Nair et al. (2000) found that the prevalence of ACD among residents of residential care facilities in the Hunter area in NSW in Australia is 0.2 per cent. For most residents, health-care decisions were made by surrogate decision-makers or on the basis of an unstated, unwritten, staff consensus regarding the 'appropriate' level of care. Formal, written directives for care, including no-CPR orders, Living Wills and enduring guardians were, in contrast, extremely uncommon. This is consistent with research from the USA, which has found that even where legislative support for ACDs exists, the vast majority of both competent and incompetent residents lack clear processes for decision-making either in the form of written directives or appointed guardians (Hahn, 2003; Janofsky & Rovner 1993; Mezey, Bottrell & Ramsey, 1996).

Living wills have been legally binding in South Australia since 1983. However, a public opinion survey conducted in 1991 demonstrated a significant lack of public awareness concerning the issue. A 1994 survey of 117 South Australian General Practitioners (GPs) found that only 41 doctors had discussed making a Living Will with patients (Ashby, Wakefield & Beilby, 1995). This finding is disappointing because it has been reported that patients may wish to be involved in their own ACP, or wish to involve a family member (Hawkins & Cartwright, 2000; Kerridge et al., 1998) and many patients want some form of ACD (Kerridge et al., 1998). A more recent study conducted in a region in NSW in 2001 also confirms that only 1 out of 40 (2.5 per cent) patients in cardiac rehabilitation programs knew about ACD, whilst all of them graded its importance as 6 or greater on a 10-point scale (Mador, 2001).



The published research regarding ACP and ACD in Australia is scant. The search conducted in August, 2007 on the literature using the database ProQuest 5000 without imposing a limit on the year of publication revealed 11 articles. The keywords used were 'advance care planning' and 'Australia'. There were four (out of 11) documents published by nursing professionals but only one was a research article (Seal, 2007). A search using the key words 'advance care planning' and 'advance directives' yielded 17 documents, however, when the search was limited by 'Australia', the database was not able to locate any documents. It seemed to be more promising when 'advance directives' and 'decision-making' were used as keywords in citation and abstracts in multiple databases, as they resulted in 105 documents. However, it was disappointing when the search found only two documents (Cook et al., 2006; Onwuteaka-Philipsen et al., 2006) when the search was limited to 'Australia'.

A literature search using another database, Cumulative Index to Nursing and Allied Health Literature (CINAHL) with the keywords 'advance care planning' and 'nursing' found 56 documents, however, only three of these articles were related to the Australian context and one of the three was a research article (Grbich, 2006). Changing the keywords to 'end-of-life decision-making' in the Australian context did locate five documents. One was a research article and one was not relevant to the current study. Of the 24 articles located through the search, three (Board, Brennan & Caplan, 2000; Brown et al., 2005; Caplan et al., 2006) were relevant to ACP and ACDs in RACFs, although they were not published by the nursing profession.

While this finding clearly underestimates the total number of publications originating from Australia, it may reflect the importance attributed to this topic in Australia, relative to other countries (Taylor & Cameron, 2002).

### **2.3 Legal aspects of ACP and ACDs in Australia**

In Australia there is no consistent legislation in relation to ACP and ACDs. Each state and territory in Australia has its own legislation governing issues surrounding end-of-life care and decision-making. Legislation in Australia providing for ACD varies between states, and this has been summarised by Beigler et al. (2000). Presently, New South Wales and Tasmania have no legislation providing for ACDs (Beigler et al., 2000; Cartwright, 2000).

In Western Australia, the ‘Advance Health Care Planning Bill’ which allows terminally ill people to refuse medical treatment was submitted to State Parliament in June 2006 (McGinty, 2006). The ‘Advance Health Care Planning Bill’ would:

- Allow adults to make an advance health directive – or Living Will – about future health matters, including the withdrawal or withholding of medical treatment and life-sustaining measures;
- Allow adults to appoint an enduring guardian to make personal, life-style and medical decisions on their behalf in the event of future incapacity;
- Enable a responsible person, such as a loved one or next of kin, to make medical decisions on behalf of a mentally incapacitated person in the absence of a Living Will or enduring guardian; and
- Provide clinicians with legal protection from criminal and civil liability to carry out the wishes of dying patients or their guardians.

(McGinty, 2006)

The existing ACD legislation in the remaining states is far from uniform, with the major differences being associated with the type of ACD, legal validity and physicians’ liability (Beigler et al., 2000). For example, South Australia and the Northern Territory allow a directive for future health care to be made at any time, but the directive applies only in the case of a terminal illness, while Victoria and the Australian Capital Territory (ACT) allow a person to sign a ‘refusal of treatment’ certificate, but only for a current illness, which does not have to be terminal. Queensland has the most recently acquired legislative scheme to allow the use of advance directives and the appointment of proxies, both generally and in terminal illness (Cartwright et al., 1997; Cartwright, 2000; Mogg, 2006; Stewart, 2005). Mogg (2006) argues that an ACD written by a person living in Queensland may be applied with limits should the person require medical treatment in South Australia. It indicates that the differences in legislation related to ACP between the states could result in overtreatment or undertreatment.

Advance Care Directives are considered as legally binding in Australia, as the law regulating the use of ACDs is a mixture of legislation and case law, and in many respects is subject to uncertainty (Clayton et al., 2007; Diamond et al., 1989). The Australian Capital Territory, Northern Territory, Queensland, South Australia, Western Australia and Victoria have

statutory schemes for ACDs. In other states, the law of ACDs is governed by common law (Clayton et al., 2007). This means that in some jurisdictions, a person can appoint someone as an enduring guardian (EG) whereby a family member or other trusted person is appointed to make health decisions on the person's behalf, should the person lose the mental capacity to make his/her own decisions. With the absence of such an appointment, all Australian jurisdictions have guardianship arrangements that recognise the authority of people close to the patient to make medical treatment decisions on that person's behalf in the event of a lack of decision-making capacity. For example, in NSW the *Guardianship Act 1987* (NSW) provides for a surrogate decision maker where a person is no longer competent to make decisions about health care. The former is known as the 'person responsible' and is defined from a hierarchy of people which includes guardians, spouses, carers and close friends and relatives. The *Guardianship Act* has been amended recently to allow persons over the age of 18 years to appoint an EG to make certain decisions, including those concerning medical treatment for them should they become incompetent (Nair et al., 2000). However, even when an EG is appointed, some health-care professionals do have a concern following ACDs about where they stand from the legal perspective, especially when an ACD involves the withdrawal or cessation of medical treatment.

With the absence of legislation specific to ACP in NSW, the Department of Health NSW published 'Guidelines for end-of-life care and decision-making' (NSW Health, 2004) and 'Using advance care directives' (NSW Health, 2004). Ms Julie Letts from NSW Health's Research and Ethics branch confirmed that advance care directives are recognised under common law in NSW and if directives are written up under these two guidelines and meet certain conditions (capacity, specificity, witness and currency) described in the guidelines, then health professionals should feel confident about following patient directives (Mogg, 2006).

While all states make provision for patients to record their desires in terms of end-of-life care, the conditions for enacting these declarations differ from state to state. The status of ACDs and the responsibilities of representatives of incompetent patients are complex and vary from jurisdiction to jurisdiction. Research on the implications of differences in legislation and variations in jurisdictions are not yet established, as the practice of ACP has only just begun and is limited in Australia. Considering that the lack of knowledge on legal

aspects of ACP and fear of litigation are the barriers in ACP that health-care professionals experience (Ball, 2006; Cartwright & Parker, 2004; Grant, 1993; Pollard, 1991; Shapiro & Bowles, 2002), research in this area should not be delayed.

## **2.4 Benefits of ACP and use of ACDs**

### **2.4.1 Practice of persons' autonomy**

One of the most commonly discussed benefits of the use of ACDs and enduring guardian for health matters is that it gives the individual and/or family members a role to retain their autonomy and authority as decision-makers in situations wherein the individual is no longer able to provide input (Duffield, 1998; Hawkins & Cartwright, 2000; Inman, 2002; Kirmse, 1998). This is considered as an evolution, as physicians traditionally have determined their patients' resuscitation status without consultation (Sayers, Schofield & Aziz, 1997). Solomon et al. (1993) found that physicians and nurses perceive that patients' and their surrogates' involvement in end-of-life decision-making is inadequate. The acknowledgment that patients theoretically have the right to decide has probably not yet caught up with actual practice (Dunlap, 1997). In contrast to the findings of earlier studies, it is noted that an individual prefers to have more control over her/his medical decision-making and the general population is in favour of having legislation that acknowledges the right to express wishes related to end-of-life decisions (Inman, 2001; Mador, 2001).

However, viewing ACDs strictly through the lens of personal autonomy is challenged. In practice the participation of nursing-home residents in their own end-of-life treatment planning is limited, due mainly to cognitive impairment (Allen et al., 2003; AIHW, 2004; Bravo, Dubois, & Paquet, 2003; Wurzbach, 2002). It is often the case that a significant family member would be chosen, either by an appointment from an older person when capable or by the law, to make decisions for the individuals who are unable to do so (Hopp, 2000; Inman, 2002). This is alarming, as studies demonstrated that family members were not able to predict older adults' preferences on medical treatment for the end-of-life care (Wurzbach, 2002).

Wurzbach (2002) found that the whole realm of residents' decision-making was changed, compared to the findings of her study in 1992. She found that the resident was the primary

decision-maker, rather than the family or physician. However, another concern with regard to the autonomy of older people in ACP and ACDs is that even cognitively intact individuals who want to practise their right to make decisions lack understanding and knowledge of their treatment options at the end of life. Sayers, Schofield and Aziz (1997) found a poor understanding of the procedure of the CPR, poor recall of information given, and in some cases evidence of harm among older patients. Frank et al (2003) also found that older patients and their families overestimated the benefits of CPR when in fact none of the older adults studied by Murphy et al. (1989) survived ACP in the nursing home.

The legal system imposes a limit on autonomous practice. Levinsky (1996) noted that it is far more frequent for patients and their families to demand aggressive treatment against the advice of their physicians than for doctors to press to continue therapy that patients or their families want to discontinue. However, not all end-of-life care wishes will be respected by medical professions and protected by the law. For example, the Melbourne University Medical Centre applied to the court to cease haemodialysis treatment for an elderly lady who was suffering from the end stage dementia and chronic renal failure, reasoning medical futility. Her son strongly refused to follow the decision made by the medical team and emphasised their right to receive all the medical treatments necessary, even if it only prolonged his mother's life (Davis, 2004).

In another case, a son of a family man who was in a coma failed in a court action to stop a hospital withdrawing his father's life support in St George Hospital in Sydney in 2004 (Wallace, Pollard & Needham, 2004). Doctors at the hospital determined that Mr Messiha, a 75-year-old man, be removed from the life support machine and placed under palliative care. According to Skene (2005), if the patient's wishes were not known, and the family, or some of them, wanted to have treatment continued, then that does not mean that they would be entitled to require that to happen. In Messiha's case in NSW, the law ordered that treatment, including artificial ventilation and feeding, be withdrawn from Messiha with severe hypoxic brain damage after cardiac arrest, despite family objections. Patients have a right to refuse treatment that they do not want, not to require that it be provided to them. If the family is adamant that treatment must be continued, their only option is to challenge the diagnosis by applying to a court. The NSW Supreme Court dismissed his family's application to have him remain on life support, saying the hospital was acting in his best interests. The stories illustrated above highlight the benefits of ACDs through ACP. Where

there is a conflict between a family member and the health-care team over ‘futile’ treatment it is likely that third-party interventions will occur. The latter would be by law in most cases and thus would result in costly, time-consuming, and financially taxing attempts to resolve such disputes where there is no formal ACD (Faunce & Stewart, 2005).

#### 2.4.2 Communication and ACPs/ACDs

A positive outcome associated with ACP and ACDs is that it, in its nature, should encourage discussion between a person and his or her practitioner about the person’s preferences by initiating communication (Clayton et al., 2007; Johns, 1996; Kirmse, 1998). Fortunately, the literature reflects that the actual process of discussing end-of-life issues stimulates therapeutic conversations between patients and health-care professionals and leaves patients and families with an increased sense of feeling cared for and understood (Miles, Koepp & Weber, 1996). The benefit of having the discussion about end-of-life care through the treatment options is emphasised decreased burden of the family members when they are left to wonder what their loved ones would have wanted (Mogg, 2006). For example, Duffield (1998) found that discussing ACDs with patients before a life-threatening illness was extremely valuable in the clinical setting. When the emotional time comes for family members to make decisions for incapacitated loved ones, many have reported that they were relieved and grateful that they had discussed and completed an advance directive with loved ones before the critical stage of illness (Duffield, 1998).

Support Study Principal Investigators (1995) suggest that preferences regarding end-of-life decisions require more than documentation to be integrated into care decisions. They need an institutional setting that promotes dialogue, fosters continuity of care at the end of life, encourages the discovery of pre-existing preferences, and acknowledges the legitimacy of palliation (Frank & Campbell 1996; Miller & Fins 1996; Solomon et al., 1996). Fins (1997) warned about the danger of limited application of ACDs without comprehensive conversation and discussion. It is often the case that the question is too narrowly cast. If the patient is simply asked whether s/he wants to be resuscitated, without being given an alternative palliative care option, the response is predictable. This reinforces the false belief that there are just two options at the end of life; resuscitation or ‘doing nothing’. Posing the question in this way will bias responses that will lead to decisions to do ‘something’ over ‘nothing’ (Fins, 1997).

Ditto et al. (2001) pointed out that ACDs should be a concerted effort to communicate what treatment is wanted with mutual understanding. Teno, Lynn et al. (1997) stressed that ACDs cannot be expected to function well without effective communication between the person and health professions involved. It appears from the literature that effective communication with mutual understanding has never been so important, given the findings of the following studies. Steihauser et al. (2000) conducted a study to expand the taxonomy of preparation, using the results of both qualitative and quantitative data. A full spectrum of persons involved with end-of-life care – physicians, nurses, social workers, chaplains, hospice volunteers, patients, and recently bereaved family members – were included. All role groups agreed that naming someone to make decisions and having those decisions in writing are important components of the preparation. However, it often meant, for patient groups, having finances in order and having funeral arrangements planned. Frank et al. (2003) also noted that there is a discrepancy between patients' wishes and physicians' understanding of those wishes.

Another caution to be taken in communication about end-of-life care issues between the person and health-care professions is to take note of the context and expectation in which the communication occurs. Fins (1997) warns that ACD documentation without acknowledging the relationships that both sustain and inform the Patient–Doctor–surrogates will result in confusion, as ACP occurs in the context of the relationship between them. A convenience sample of 55 adults age 50 or over in Inman's study (2002) indicated that they would feel comfortable discussing end-of-life wishes with a physician, whilst many physicians believe that it is the patients' responsibility to initiate discussions. Hopp (2000) alerted that the discussion of end-of-life care preferences and completion of ACDs have occurred during informal communication. However, the types of issues covered in these informal discussions, the context and process by which these conversations are initiated with family members and other potential health-care surrogates are yet to be disclosed.

The discussion about end-of-life care with loved ones is described as fundamental. As people live longer and the incidence of dementia is increasing, Professor Abbey from the University of Queensland believes that knowing people's wishes before they become incapacitated is vital (Mogg, 2006). It was pointed out that unless there is adequate

communication between patients and health-care workers, advance directives are unlikely to improve the decision-making process (Molly et al., 2000; Teno, Lynn et al., 1997).

#### 2.4.3 Cost-effectiveness

Taylor and Cameron (2002) suggested that one of the interesting impacts of ACP will be the potential reduction in medical resource expenditure in inpatient and outpatient acute hospital services; acute hospital access; therapeutic and ancillary services; and general medical practice. Duffield (1998) emphasised that ACDs hold the promise of the more humane use of life-sustaining treatment. It was clearly noted in the literature in the 1990s that the focus of studies had paid attention to the cost-effectiveness of ACDs. For example, Weeks et al. (1994) found that patients without ACDs have significantly higher terminal hospital charges than those with ACDs. Their investigation suggests that the preferences of patients with ACDs are to limit care and these preferences influence the cost of terminal hospitalisation.

Even when the purpose of the ACP is not cost containment, there may be a philosophical emphasis on limiting, rather than maintaining treatment. For example, Gillick (1995) described ACD as a method to avoid excessive and undesired interventions in the final years of life. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) has greatly expanded empirical knowledge of end-of-life care and the inadequacies of practice (Fins, 1997). On the premise that those who complete a Living Will generally intend to limit life-sustaining treatment, the SUPPORT study, an extensive investigation of the use of formal advance directives among seriously ill patients, focused on the potential for the reduced use of resources (Teno, Lynn et al. 1994; Teno, Hakim et al. 1995). The investigators in the study examined practice patterns before and after the implementation of the PSDA of 1990. The papers collected focus on the effectiveness of ACDs to influence care and promote savings at the end of life. Interestingly, the investigators concluded that ACDs fail to enhance communication and that their use does not result in a reduction of costs.

A large amount of research has been undertaken overseas to determine whether ACP and ACDs do, in fact, decrease the cost of health care. None of the individual studies of cost savings at the end of life that are associated with ACDs, hospice care or the elimination of futile care is definitive (Taylor & Cameron, 2002). Confusion between advance planning as



a method to find out what the patient wants and advance planning as a mechanism to reduce medical care and thereby contain costs represents a clear danger to the goals of informed consent and autonomy for patients (Levinsky, 1996). It is important to emphasise that the principle of ACP is based on respect for patient dignity and autonomy, rather than on health-care costs (Taylor & Cameron, 2002).

Recently in Australia, however, Caplan et al. (2006) evaluated a program for educating nursing-home residents, their families, staff and general practitioners about the outcomes of dementia, advanced care planning and the concept of 'hospital in the home (HITH)'. The findings of this study showed that the financial benefits of ACDs and HITH were not conclusive, however, the quality of life of the residents maintained in the nursing home and satisfaction from the families and nursing staff with a good death amongst friends and loved ones in the nursing home were undoubtedly and potentially more cost-effective.

#### 2.4.4 Directions from advance directives

Another positive outcome of ACP and ACDs is that health-care professionals will be guided by advance directives written with regard to end-of-life care decision-making. There have been questions about the way doctors reached a decision has been questioned, that is whether to provide a person with what treatment and to what extent. Considering that doctors believed themselves to be the preferred decision-maker, it is a concern that doctors caring for very sick patients focus inordinately on technology rather than on the patient. Doctors are determined to keep dehumanised bodies alive indefinitely, whatever the cost in human suffering or money. Therefore, ACDs are viewed as a tool to prevent doctors from extending life against the wishes of patients or their surrogates, rather than as a neutral means to ensure that medical care is guided by patients' preferences (Levinsky, 1996).

It is also important to note that doctors' response to ACP varies, related to the way they view and act upon it. A number of research studies have found that the decisions made by medical officers could vary depending on their training, beliefs, and perceptions. Steinberg, Cartwright et al. (1997) reported that both GPs and community members support the use of ACD but differ significantly with regard to barriers preventing their use. Furthermore, physician management appears to be determined largely by the characteristics of the doctor

and not solely by the nature of the medical problem (Steinberg, Najman et al., 1997; Ryan, 1996).

Therefore, another important benefit of ACP is that participation in the informed consent process and in the preparation of ACDs would enable health-care professionals to be familiar with patients' and families' wishes and could reduce variations of treatment related to socio-demographic and medical training factors (Waddell et al., 1996). For example, Waddell et al. conducted a postal survey to a national sample of 2,016 doctors in Australia in 1995. In the study, they found that directives appear to give doctors directions in making medical decisions (Waddell et al., 1997). Duffield (1998) mentioned that having an ACD on file in primary care has made it easier in that nurses can quickly review ACDs and discuss end-of-life decisions with patients and their families with greater ease. Schiff et al. (2006) also found that 78 per cent of 842 members of the British Geriatrics Society (BGS) reported that the Living Will (advance statements) had made decisions easier.

As pointed out by Taylor and Cameron (2002) doctors, would not have to wonder to what extent they had to provide care to the older person who presents in hospital with multiple health breakdown and who does not have many prospects for the future. They suggested that where patients and health professionals 'engage in a process of reflection, discussion and communication of treatment preferences for end-of-life care that proceeds, and may lead to, an advance directive' should give health professionals clear directions in making medical decisions. It is alerted that regimes which merely create forms of advance directive, will fail to improve the correspondence of patients' preferences with the treatment they actually receive.

However, the potential benefits of ACP and ACDs will never become real unless the following issues raised are addressed. Future research is needed in Australia to determine the process that leads to end-of-life decision-making and action in clinical practice, and the factors that determine who ultimately makes a treatment decision, what influences treatment choice, and how the treatment is carried out (Mador, 2001; Phillips et al., 2006; Stewart, 2005; Waddell et al., 1996).

## 2.5 When, why and how of ACP and ACDs in RACFs

An understanding of the benefits of ACP and ACDs has led to questions about when and how they should be presented to health-care consumers and their loved ones. There have been consistent attempts to implement ACDs in home care, hospital, and long-term care settings. Not surprisingly, people do not want to talk about palliative care at the commencement of a life-threatening illness (Chiarella, 1994; Mogg, 2006). It was recommended that the discussion regarding prognosis and treatment options should occur in the early stages of a life threatening illness, and that second opinions should be offered at that stage if there were any doubts or disagreements. Basile (2002) also suggested that it is best to complete ACD when there is a non-crisis situation. For example, Ratner et al. (1999) found that 20 per cent of deaths for the general population in Minnesota occur at home. However, the reluctance to talk about ACP by many clients in home-care services was noted to be due to misconceptions and fears about the health-care directive form. Patients have stated that they are fearful that completing the ACD form would mean that nothing would be done for them at all, in all circumstances, including aggressive pain and symptom management (Norlander & McSteen, 2000). The authors found that the majority of the home-care consumers expressed a desire to receive end-of-life care at home and 80 per cent of the participants were able to remain at home with hospice services after ACP discussion with home-care nurses, clarifying these misconceptions and allaying unfounded fears.

The RACF setting provides nurses with a unique opportunity to play a significant role in ACP with residents and their families. Teno, Branco et al. (1997) highlighted two important concerns about ACP and decision-making at the end of nursing-home residents' lives. Less than one in five residents has a Living Will or durable power of attorney. These results are consistent with previous research of ACP that has shown that the majority of older persons and those who reside in long-term care facilities have not completed a written advance directive. Hence, the majority of decisions will need to be made either through an informally named surrogate or by a guardian named by a court of law. In addition, it was noted that decision-making about hospitalisation of nursing-home residents is a more important concern than resuscitation (Allen et al., 2003; Carr & Khodyakov, 2007; High, 1993; Teno, Branco et al., 1997; Wurzbach, 2002). It often becomes frustrating for families and nurses regarding whether to send the older person to a hospital or not, without clear

written directives. The growth of sophisticated life-sustaining technology, the apparent interest of the older people in participating in decision-making and the increasing number of incompetent residents in nursing homes all argue for greater exploration of the process of ACP in residential aged-care settings (Ball, 2006; Nair et al., 2000).

## **2.6 The barriers to and predictors of ACP and ACDs**

Various studies discuss and suggest numerous barriers to explaining the difficulties with ACP and lack of completion and implementation of ACDs in practice. The researcher classified those barriers in three areas: (a) barriers to ACP discussion; (b) barriers to ACD completion; (c) barriers to ACD implementation.

There are various misconceptions that hinder initiation of ACP discussion. Unfortunately, patients seldom initiate the conversation, nor do their physicians (Basile 2002). The possible reasons suggested by investigators are procrastination, dependence on the family for decision-making, waiting for the physician to initiate a discussion, and the physician waiting for the patient to initiate a discussion, poor wording in advance directive documents, lack of training of medical practitioners in discussing death and dying, and fear of causing emotional effects on their patients by doctors (Cartwright, 2000; Stewart, 2005). Many studies have found that patients would like to discuss their preferences for end-of-life care and that a common reason for not having done so is that the physician never raised the subject (Cartwright, 2000; Emanuel et al., 1991; Gamble, McDonald & Lichstein, 1991; Virmani, Schneiderman & Kaplan, 1994). Clayton et al. (2007) alerted the health professionals not to assume that the patient does not want to discuss the topic simply because he/she does not raise the issue or because of cultural background.

Patients seldom initiate conversations regarding the ACD, and even with good intentions, the forms often do not get filled out. Some, who initiate conversations with a family members, are met with fear and opposition (Basile, 2002). In addition, the Western culture deals poorly with death, as the topic in general seems to be taboo (Basile 2002; Steinhäuser et al., 2001). Chiarella (1994) claimed that society should have the same normalisation of the notion of dying with dignity as in the topic of organ donation, in order for people to accept ACP.

The literature reveals several barriers to the completion of ACDs. Various studies discuss and suggest the barriers to explain the lack of ACD completion. Race and culture has been one explanation for the low completion rate. Those who have completed ACDs are often known to be older, white, well-educated, and of higher socioeconomic status (Basile, 2002; Douglas & Brown, 2002; Hopp, 2000; Murphy, 1996). The ACD executors are reported to have more numerous occurrences of personal experience of witnessing and enduring the effects of a terminal illness or critical injury on a family member or friend than nonexecutors (Carr & Khodyakov, 2007; Havens, 2000; Miles, Koepp & Weber, 1996; Mansell et al., 1999). The association of religiosity and ACD execution is a new finding in Havens' study (2000). It is possible that those with stronger religious commitments are sustained by these values, and thus are more pragmatic about planning for this phase of their lives. The complexity of the decision to document an ACD and how the frail aged, those over 85, might be considered differently from the relatively young aged, those under 85, are also barriers to the completion of ACDs (Dunlap, 1997).

Patient's belief of fatalism, or the acceptance of the 'Will of God', fear of 'signing my life away', and fear of not being treated are also important reasons for the low completion rate of ACDs (Elpern et al., 1993; Gamble, McDonald & Lichstein, 1991; LaPuma, Orentlicher & Moss, 1991; Emanuel et al., 1991). Other significant barriers to the completion of ACDs are lack of knowledge about ACDs. Hawkins and Cartwright (2000) found that 70 per cent of those surveyed indicated that they would like to know more about ACDs. They also confirmed that the current usage of ACD was low mainly, due to a lack of familiarity with ACDs. The fundamental nature of familiarity with ACD documents to ACD completion was affirmed in the study by ACD executors who reported greater familiarity with ACD documents than did nonexecutors (Havens, 2000).

It is possible that ACD executors do not fully and accurately comprehend the role of Living Wills or DPAHC in their end of life (Havens, 2000). Or, considering the complexities of completion and follow-up process, they may believe that they need a lawyer to fill out the forms (Glick et al, 1998; Taylor, 2002). Gillick (1995) identified two primary needs of patients and families as they complete ACDs. The first need of the patient and family is to not be deprived of hope. However, unrealistic appraisal of their clinical picture, or no appraisal at all, may promote the patient's desire for futile and overly aggressive

treatment. The second and most important need of patients and families is that they are assured that they will never be abandoned and that every effort will be made to optimise the highest quality of life in their remaining days.

It was inconclusive whether education sessions would increase knowledge and understandings about ACP, and promote documentation of ACDs. For example, ACD educational experiences promote ACD execution in a study conducted by Havens (2000). However, a geriatrician-led education session for clients who attended a cardiac rehabilitation program did not exhibit any significance in the completion of ACDs in a region in Australia (Mador, 2001). It was suggested that health-care professionals, particularly nurses who are most frequently the professionals with patients and their families during the dying process, should incorporate ACD into their educational endeavours (Ball, 2006; Havens, 2000; Inman, 2002; Wurzbach, 2002).

However, there are more complicated barriers to the implementation of ACDs. The accessibility of ACD documents was questioned by several investigators. Haynor (1998) noted a review in which physicians were not even aware of ACDs in the hospital chart. In some cases, ACDs had been prepared but were not accessible to medical staff at the critical moment. In other cases, although an ACD had been prepared and was accessible, it had been disregarded (Taylor & Cameron, 2002). Of the 9,105 patients treated in five teaching hospitals in the USA, investigators found that only 688 patients (less than 10 per cent) had written ACDs, with two-thirds of those (458) in the form of durable power of attorney. Sadly, three in four physicians were unaware of these patients' ACDs, even though they were part of the patients' medical records and only 3 per cent of the ACDs were specific enough to affect care decisions (Haynor, 1998).

Even if a patient has an ACD that has been agreed upon by all family members, things can go wrong in the community setting. For example, despite being her ACDs being legally documented, when Ms Brown suffered a respiratory arrest the emergency medical team intubated her and placed her on a ventilator before transporting her to the local hospital. This distressing situation caused another week of suffering for her and her family members (Haynor, 1998).

Barriers to the implementation of ACD documents persist including challenges to the validity of the documents (Havens, 2000; Taylor, 2002). Minimal input from physicians is another encumbrance to promoting ACDs. A study showed that when doctors engage in conversation about ACD they spend fewer than six minutes (Meyer, 2000), and the time is rarely spent examining the patient's individual values (Basile, 2002). Markson et al. (1997) surveyed 1,050 physicians in the USA to examine their behaviour with regard to advance decision-making. Most doctors (82 per cent) thought that helping patients select advance preferences for end-of-life care was an important part of their professional responsibilities. This was a role they tended to claim for themselves exclusively. However, it is interesting to note what they seem to believe their role. Most of these doctors (88 per cent) would try to change a patient's decision that was not medically reasonable or not in the patient's best interest. This finding needs special consideration regarding the doctor's role, as a number of studies suggest that doctors may place a different value on medical interventions from those of the patients they are supposed to represent and may not predict patient preferences accurately.

An understanding of the barriers to ACD completion led to methods to increase completion rates. Successful methods have included: (i) community-based education, (ii) individual education and counselling sessions by physicians and nurses, (iii) educational literature, (iv) video tapes, (v) primary-care provider education and (vi) computer-generated physician reminders (Taylor & Cameron, 2002; Miles, Koepp & Weber, 1996). The best timing and environment for ACDs discussion suggested in literature might be a practitioner's office, in a continuing-care retirement community, or in a day-care setting (Haynor, 1998).

## **2.7 The roles of nurses in ACP and ACDs**

Shapiro and Bowles (2002) raised the issue of the need to evaluate who should initiate and present the information about ACP to health-care consumers and their loved ones. The Australian Nurses and Midwifery Council (ANMC) sees the nurse's role as including the provision of assistance to the dying, to help them achieve a dignified death (ANMC, 2006; Cartwright et al., 1997). Aranda and O'Connor (1995) stress the importance of nurses being involved in discussions concerning end-of-life care. The concept of holistic care has also been the core concept of nursing for many years. ACP requires a holistic approach

that includes physical, psychosocial, and spiritual factors. Norlander and McSteen (2000) said that the facilitation of ACP is an example of holistic care that results in improved communication and trust, well-being, and patient and family satisfaction. It is evidenced by Haynor's study (1998) that discussions with nurses about ACDs increase the probability that a patient will complete one.

However, many nurses have not been involved in implementing advance care directives with their patients and families, in part, because of the traditional model whereby doctors are regarded as being responsible (Elpern et al., 1993; Cartwright, 2000). For example, one of the most frequently cited concerns about ACD completion was the lack of communication between doctors and nurses, and/or doctors and patients/patients' families. Although nurses are the primary care-givers, and spend much more time with patients and their families than do doctors, nurses' opinions are often overlooked (Cartwright et al., 1997). Critical care nurses (CCNs) are frequently excluded from the decision-making process, despite the fact that their inclusion could positively impact on the management of the dying patient (Witham & AAP, 1996 in Cartwright, 1997). Chiarella (1994) also pointed out that nowhere does the word 'nurse' appear, and no reference is made to nursing care, or to the possibility of anyone other than a doctor being the key practitioner for a patient in the 'Interim guidelines on the management of dying with dignity' published by the New South Wales Health Department in 1993.

Optimally, the instructions in an advance care directive should instruct a substitute decision-maker (proxy), not the attending physician (Waddell et al., 1997). However, decisions have been mostly made by doctors in consultation with family members but in the survey 46 per cent of adult patients ( $n = 100$ ) did not indicate that doctors were acceptable decision-makers (Hawkins & Cartwright, 2000). This result is not surprising, given that the SUPPORT (Support Study Principal Investigators, 1995) study shows that doctors are biased toward aggressive treatment but, rather, that they often fail to understand their patients' wishes. In addition, Inman (2002) found that some respondents indicated they would feel most comfortable discussing end-of-life wishes with a physician, whilst many physicians believe it is the patients' responsibility. In a recent survey of 842 geriatricians in the UK, very few (6 per cent) of them had helped someone construct a Living Will or advance directives (Schiff et al., 2006).



Secondly, the older people may not believe that they require ACP for themselves and they may prefer their health professionals or families be responsible for end-of-life decisions (Inman, 2002; Sansone & Phillips, 1995). However, Waddell et al (1996) found that doctors did not make consistent decisions on the treatment of severely and terminally ill patients at the end of life. They suggested that there are no uniform criteria to guide doctors in managing such clinical situations. If these decisions are left solely to doctors, then the outcome will vary systematically, according to medical training and sociodemographic factors. The results of the SUPPORT study also indicate that despite ACDs documents and several specific interventions, doctors did not readily change their behaviour when making treatment decisions for patients at the end of life (Cartwright, 2000; Support Study Principal Investigators, 1995; Waddell et al., 1997).

Thirdly, the realm of nurses' participation expected in ACDs appears to have changed. Directives should enhance individual autonomy, whether that relates to a decrease or an increase in the level of care (Waddell et al., 1997). Recently, the paternalistic approach has been challenged and replaced with a model that emphasises patient autonomy and the right of individuals to participate in decisions relating to their medical treatment (Kirmse, 1998). In the 'Guidelines for decision making at the end-of-life (NSW Health, 2004, p. 5), it is clearly stated that

Nurses play a significant role in providing clinical and social information about or to the patient and family; in the potential initiation of treatment limitation discussions and as managers of the dying process. Nurses must be part of the collaborative process whereby the treating team develops a management plan with patients and/or their families.

Inman (2002), Douglas and Brown (2002), and Norlander and McSteen (2000) suggested that initiation of discussion of ACP is nurses' responsibility, since nurses have better understanding of patients' perspectives on their illness, although physicians know more about the prognosis and treatment of a patient's particular diagnosis. Kirmse (1998) also pointed out that because nurses spend more time with patients and their families than any other care-giver, they play an important role in developing and implementing ACDs. Steinberg et al. (1997) found considerable differences in opinions and attitudes towards end-of-life decisions when they compared community members and medical practitioners. Cartwright et al. (1997) surveyed 1,200 health professionals, including GPs, specialists and nurses to examine the knowledge, attitudes and beliefs about end-of-life decision-making.

In contrast to the physicians' lack of awareness of what their patients and families might want, interestingly, the responses from nurses on advance directives, proxies, pain management and physician-assisted suicide were very similar to the responses of community members. Critical Care Nurses (CCNs) showed higher levels of support for withdrawal of life support, physician-assisted suicide and euthanasia than did other health professionals overall, and their opinions were more closely aligned with those of members of the community than were the opinions of other groups of health professionals. The closeness of CCNs views to those of community members would seem to support their belief that they would be useful advocates.

Nurses often facilitate communication between patients, families, and physicians. Nurses need patient information about wishes regarding treatment in order to create effective care plans and fulfil the role of patient advocate (DesRosiers & Navin 1997; Neuman & Wade 1999; Shanley & Wall, 2004). In Larson's (1994) qualitative study of patients' values and preferences in a coronary care unit, patients wanted to be involved in discussions. The patients stated that they were comfortable discussing their feelings with nurses and that nurses were important both in providing clarification about confusing terminology and making informed decisions. Clinical experience supports Larson's (1994) and Silverman, Fry and Armistead's (1994) findings that patients are receptive to nurses' teaching about advance care directives and end-of-life treatment planning.

Despite the fact that the nurses believed that it was a nursing responsibility to encourage patients to discuss treatment wishes with family members (Weiler, Eland & Buckwalter, 1996), several studies found nurses' discomfort in discussing ACDs, lack of knowledge, lack of support, and legal and ethical concerns. Jarr, Henderson and Henley (1998) found that nurses did not feel they have adequate time or knowledge to discuss advance care directives. Barta and Neighbors (1993) used a questionnaire to assess nurses' knowledge of and role in assisting patients with end-of-life decision-making. This study concluded that the majority of nurses were not prepared for their role as patient advocate with regard to ACDs, because they did not feel comfortable discussing the subject, and that further education was needed. Barta and Neighbors (1993) highlighted that nurses should be encouraged to complete their own ACDs in order for them to better understand what ACD is and how ACD should be documented. Several authors emphasised the importance of education for nurses, particularly in the areas of patient autonomy ethics and legal issues

related to ACDs. It is conclusive that nurses were unprepared to discuss ACDs with patients, and that education about patients' right to make decisions and ACDs was needed (Crego & Lipp 1998; Jarr, Henderson & Henley, 1998). Nurses consistently reported they would benefit from additional education to better fulfil their role as patient advocates concerning end-of-life decision-making (Shapiro & Bowles 2002).

Haisfield et al. (1994) identified that the qualities needed by the nurse to address ACDs are neutrality, compassion, availability to answer patient and family questions, and knowledge of ACDs. The role of the nurse as educator and advocates includes assisting the patient to clarify understanding of ACDs, and correct misconceptions (Douglas & Brown, 2002; Haisfield et al., 1994; Seal, 2007). There is a need to learn techniques to discuss end-of-life issues sensitively, yet realistically (Shapiro & Bowles 2002). DesRosiers and Navin (1997) described the need for effective nurse education relating to patient autonomy, cultural sensitivity, and increased communication skills.

On the other hand, Mezey, Bottrell and Ramsey (1996) pointed out that knowledge and understanding of ACDs are not sufficient to ensure that the documents are followed. This also would support the idea that those who cannot or will not follow ACDs are not going to be effective or sensitive to patient autonomy when discussing ACDs. It is only possible to carry out this role successfully if one's personal values and beliefs have been addressed (Shapiro & Bowles, 2002). Personal values are derived from one's personal morals and ethical beliefs, which may be influenced by many factors. Gender, age, cultural background, ethnic background, education, income, marital status, religion and life experience contribute to an individual's view of the world, and may influence approaches to decision-making concerning medical treatment choices (Shapiro & Bowles, 2002). Crego (1999) stated that nurses must first clarify personal values. Crego (1999) further explained that evaluation of personal wishes and choices provides insight into patient decisions. It is also essential to assess patients' religious and cultural beliefs about end-of-life choices, understanding that opinions will vary and ambiguity surrounds these complex issues. This is supported by a cross-sectional study conducted by Ejaz (2000) that was designed to evaluate the influence of religion and personal values on attitudes toward life-sustaining efforts. The study concluded that nurses need to discuss these two issues in order to understand and respect treatment choices.

Education of all the parties involved in ACP is essential to increase understanding and practising of ACDs. This is supported in the literature from three different aspects. First, there were studies addressing the need to educate elderly well. Glick et al. (1998) and Ott (1999) found that elderly patients accept death and dying as part of reality, and welcome discussion of choices about future care. Second, there is a lack of physician initiative to approach the subject as a barrier from the patient perspective (Shapiro & Bowles, 2002). Finally, Meyer (2000) asserts that nurses also need to address patients' lack of knowledge about ACDs through patient teaching.

In summary, nursing has welcomed holistic care, but often is not given 'permission' to discuss end-of-life care. That role and ultimate decision-making has historically been undertaken by physicians. There has been a change in the roles expected of nurses in that if nurses are to be trained to give spiritual guidance, then nurses should be encouraged to enter as a partner in that role (Basile, 2002). The literature includes substantial discussion of the nurse's role in discussing ACDs with patients (Crego 1999; Douglas & Brown, 2002; Inman, 2002; Mezey, Bottrell & Ramsey, 1996; White, 1997; Wurzbach, 2002). There is a consistent agreement that nurses serve an important role as patient advocate, ensuring that patients are informed of their rights and that decisions are known to the health-care team and respected (Crego & Lipp, 1998; Ott, 1999).

In RACFs, nurses must understand the crucial role they play in facilitating these discussions and work closely together to help the patient and family identify the options available and the conversations that should take place before decisions are reached. Talking with a patient about care wishes and goals at the end of life can be the most important discussions that nursing home nurses have (Norlander & McSteen 2000; Mogg, 2006; Wurzbach, 2002). Despite the emphasis on the roles of nurses in ACP and ACDs in long-term care facilities, it is disappointing that less than 8 per cent of participants indicated nurses as the desired educator for ACDs (Inman, 2002). Nurse facilitators were used to provide advice and information as well as documenting patient and family preferences in the well-funded SUPPORT trial, without any noticeable improvement in the control of patients over their treatment (Support Study Principle Investigators, 1995). This suggests that nurses may not be able to perform their role to the fullest extent unless the following issues are addressed. Nurses expressed this role as the most difficult to perform. Too often critical end-of-life care discussions are delayed until a patient is in crisis or too close to death to participate

(Carr & Khodyakov, 2007; Mogg, 2006; Norlander & McSteen, 2000). Lack of knowledge about advance directives was also mentioned by nurses themselves (Cartwright, 2002; Stewart, 2005). The existence of relatively few research articles by nurses suggests that nurses are not heavily involved in research regarding ACP and ACDs. Therefore, a more achievable goal for nursing at this point is to investigate the level at which nurses are performing in ACP at present and the scope that nurses can expand to in the future. This goal is especially relevant to nurses in the Australian context, as there is little known about nurses' participation in ACP and ACDs.

## **2.8 Autonomy and clinical application of ACP**

ACP is consistent with the increasing importance placed upon rights, autonomy and patient/consumer participation in health care and has received broad public and professional endorsement (Stolman et al., 1990). However, research from the USA indicated that the concept of ACP and the clinical application of ACP have failed, due to the lack of understanding of an individual in a moral relationship, economic rationalism, standardisation of medical futility, and absence of empowerment. Discussing these factors is an integral part of the literature review, as it provides the researcher with more of an in-depth understanding of the phenomena of ACP and ACDs. The following section discusses these factors.

### **2.8.1 Autonomy in a social context**

The ACP motivates an individual's desire to participate in and to control treatment decisions as a way to exercise personal autonomy and self-determination during periods of incapacity, and has been welcomed by both patients with terminal diagnoses (Skilbeck & Payne, 2005; Sulmasy, 1998) and by the majority of old people (Gordon & Shade, 1999; Lambert et al., 2005). Media described ACDs as personal and individual decisions that resulted in the pragmatic utility of ACDs in directing one's end-of-life treatment (Havens, 2000). Portraying an ACD as enhancing one's personal autonomy, however, is an incomplete representation of an individual within a social context and the document's moral significance. The exercise of personal autonomy cannot be perfected until one understands that an individual exists within a community connected to relationships with family members, surrogates, friends, and health-care professionals. Havens (2000) explains

this as a moral relationship and that it is this morality of care that will enrich the decision-making process surrounding the execution of an ACD.

An individual's discussions with others about his or her end-of-life care and surrogate appointment, and the extent of a patient – physician relationship are empirical indicators that have been reported to be associated with the execution or nonexecution of ACDs. For example, in a study of dialysis patients' preferences for family-based advance care planning, when interviewed, 93 per cent of haemodialysis patients reported having discussed specific treatment preferences with a family member or spouse, while 48 per cent wished a family member or spouse to lead the conversation about desired treatment if the patient was too ill to do so (Hines et al., 1999). Eighty-two per cent of respondents who reported having a discussion about advance directives stated that the discussion was with family members. The discussion rate was significantly correlated with older people who admitted to having a close relationship with siblings (Inman, 2002). When individuals had not spoken with anyone about end-of-life issues, the major barrier reported was not wanting to upset loved ones (Sulmasy et al., 1998). Interestingly, respondents in the study conducted by Havens (2002) reported being more fearful of becoming a burden on their family than they were of death itself and valued relieving family members of having to make treatment decisions and of the physical and financial responsibilities related to their end-of-life care. It is clear that individuals practising autonomy perceive a significant role for family in the completion and use of ACDs.

### 2.8.2 Autonomy in an era of economic rationalism

Levinsky (1996) pointed out that ACP is an important means by which patients and physicians can work together to set the guidelines for care, should the patient become acutely ill. This appropriate goal is in danger of being entangled with other issues, such as the pressure to reduce care at the end of life, and the economic pressures exerted by society and insurers, all of which push doctors and others in the direction of reducing care. Although the literature is not conclusive on the effectiveness of costs for end-of-life treatments for patients with/without ACDs, ACP has been seen as a means for economic rationalism rather than for optimising care of the individual (Schneiderman et al., 1992). Concern about the substitution of cost for clinical appropriateness as the basis for advance planning is especially pertinent to the care of the old people (Levinsky, 1990). Theoretically, ACP and ACDs should enhance individual autonomy, whether that be for a decrease or an

increase in the level of care (Waddell et al., 1997). Philosophers, ethicists, politicians and health-care planners have targeted the older adults as users of excessive medical resources. There are negative attitudes toward the value of additional life for the old people in our society (Levinsky, 1996). This is evident in the cases of Messiha – a 75-year-old man in a coma – and his family, as the Court ordered his treatment to be withdrawn, whilst the Court allowed a 35-year-old man who was in a permanent vegetative state due to a drugover dose to maintain life -sustaining support (Wallace, Pollard, & Needham, 2004).

### 2.8.3 Autonomy within the context of standardisation

Dunlap (1997) claimed that medical futility justifies ACD implementation. However, there is inconsistency in the definition of medical futility between health-care professionals and patients. Taylor (1995) described futility from the disparate views of the clinician and the patient. Futility from the patient's point-of-view is treatment that is medically indicated but not valued by the patient; and from the clinician's point of view is valued by the patient but not medically indicated (p. 301). In addition, the definition of medical futility entails the importance of physicians' ability to predict the outcomes of the proposed treatment to an individual. The physician's verdict on an aggressive treatment may play a key role to the patients and their family members in exercising the right to make decisions at the end of life. O'Brien et al. (1995) found that the desire for CPR decreased when outcome data were given to older people. Consent or refusal cannot be considered as informed unless outcome data are included in the instruction. This has led to the development of tools that will provide doctors and patients with simplified justification for the decisions they may make.

However, attempts to standardise and quantify medical futility have suffered from the variability of clinical situations (Dunlap, 1997). For example, patient scoring systems such as the Acute Physiology, Aged, Chronic Health Evaluation (APACHEP) III (Knaus, 1991) and the PreArrest Morbidity (PAM) index have some potential usefulness in predicting which patients will be unlikely to respond to CPR (Ebell, 1992). The usefulness of these tools is questioned under the incidence of false positives, particularly in an evolving and/or unexpected medical crisis that limits their usefulness. Curtis et al. (1995) warned that the complexity of end-of-life decision-making and the weight that the prognostic skills of the

clinician are given in that situation can compromise the patient's autonomy. They concluded that the attempt of standardisation of medical futility was not effective in helping decision-making but did impact negatively on patients' autonomy. Byock (1996) criticised the profoundly personal nature of experience in end-of-life decision-making and dying often seemed unrecognised by the mega health-care system. It is alarming that in a recent study, 517 (of 781) geriatricians in the UK reported that an expression of wishes for health-care proforma specifically designed for the older people would be useful in their practice, despite all of the criticisms on the standardisation of medical morbidity and prognosis (Schiff et al., 2006).

#### 2.8.4 Autonomy without empowerment

The PSDA encourages the public, and patients in particular, to claim their rights in medical decision-making. It is questioned whether exercise of autonomy is possible without the individual executing the rights being educated and empowered. A number of projects were undertaken to increase the number of ACDs completed among the general public. There is evidence that most physicians now accept the authority of patients and their surrogate decision-makers to choose treatment (Fassier et al., 2005; Levinsky, 1996). Moreover, there is considerable evidence to suggest that older people are willing to participate in decision-making regarding their own care but infrequently have the opportunity to do so (Bradley et al., 1997). Nair et al. (2000) found that formal processes for ACP are uncommon in the residential-care population; it is happening informally by staff consensus. This is a practice that should be discouraged because it does not promote autonomy, and is vulnerable to individual interpretation, preferences and beliefs of staff.

In the 1990s literature, the studies focused heavily on how to disseminate what an ACD was and how to promote documentation of ACDs. This effort was justified by the fact that the ACDs emerged in the early 1990s and older people may not be informed about their rights for health care, or not be provided with opportunities to discuss ACP by their physicians (Molloy et al., 1996). Haynor (1998) revealed that despite the heavy distribution of information packages through hospital pre-admission packets and community resources, the response to ACD execution has been minimal in America. This is not surprising, given that a California group providing educational information on ACDs relates that only one in five people knows what ACDs are, which means that 80 per cent of the recipients of the



packages remained unaware and uninformed (Haynor, 1998). Less than 20 per cent of patients with chronic health conditions have completed a Living Will (Jacobson, cited in Heffner & Barbieri, 2001). Of those with completed Living Wills and DPAHC, many patients demonstrate poor understanding of the contents of their ACDs.

Interestingly, in the literature published after 2000, it was identified that the majority of the population supports the right to express wishes related to end-of-life care. Whilst it is praised for increased public awareness of their rights for end-of-life care decision-making, nevertheless, documentation of ACDs is still low and the search to determine reasons why people do not discuss or formalise ACDs continues (Carr & Khodyakov, 2007; Douglas & Brown, 2002; Inman, 2002; Lambert et al., 2005; Wurzbach, 2002). It was noted that all the materialistic information packages seemed to be produced in vain, without empowerment of individuals through person-centred education to be able to make fully informed decisions with regard to health care at the end of life.

A majority of nurses in a study conducted by Weiler, Eland and Buckwalter (1996) indicated that the patient should have as much or more control than health-care providers. It is essential for the patients and their families to be fully informed before they are asked to make decisions for themselves. There are well-recognised clinical circumstances in which CPR and other aggressive treatments are exceedingly unlikely to be effective in returning a patient to a reasonable quality of life and should not be attempted (Frank et al., 2003; Sayers, Schofield & Aziz, 1997). Health-care consumers may not always be aware of the consequences of the decisions they made. For example, in the SUPPORT study, the majority of patients who were seriously ill such that half were expected to die within six months preferred vigorous treatment to extend their life Teno et al. (1995). Some of the patients who rejected resuscitation wanted other forms of aggressive treatment (Phillips et al., 1996). The aggressive treatment of seriously ill patients was effective in extending life but not necessarily in bringing quality of life. Levinsky (1996) claimed that the patients suffered longer when the health-care team underperformed their key role in offering advice to patients and their families about the potential benefits and burdens of the proposed therapy in each individual case. Levinsky (1996) pointed that execution of autonomy without consumers being fully informed could result in an exacerbation of suffering by extending life.

Sayers, Schofield and Aziz (1997) proposed that subscribing to autonomy as a general principle needs to be balanced against particular cases where distress may be caused by, or result in, diminished competence and limited autonomy. Levinsky (1996) concluded that ACP must remain a mechanism for informed consent, by which the patient's wishes can be evaluated and brought into line with the realistic possibilities of medical care. It should not become a subtle or subconscious mechanism whereby physicians shift their role from that of care-givers to that of propagandists for limited medical treatment. Dunlap (1997) suggested that in the teaching process of ACDs, one must first assess the client's learning needs and assess the learner's readiness and ability to learn. It should also allow older persons the opportunity to explore what is important to them about life and how they would die if given a choice.

## **Conclusion**

In conclusion, in recognising the personal and social costs associated with end-of-life medical care that may prolong not life but suffering, or disturb nature in taking its course, increasing attention has been paid to ACP and ACDs. Advance care planning and advance care directives were particularly relevant and promoted as beneficial to the residents and families in long-term care facilities because of the high prevalence of incompetent residents and possibility of exposure and/or demand for life-sustaining medical treatment at the end of life. Even though the cost-effectiveness of ACDs is not conclusive, the benefits of participating in ACP and documenting ACDs are well documented in promoting one's autonomy, facilitating communication between the person–family member–doctor, reducing family burden and providing directions to health-care professionals. Nevertheless, its documentation rate and implementation of written wishes remain considerably low and impose a dangerous question concerning whether it is worth pursuing. The barriers identified in initiating, documenting, and implementing ACP and ACDs were reviewed, and it was concluded that the benefits of ACP outweigh the barriers to and difficulties with ACP and that the search to overcome the barriers needs to be pursued.

The shift from disseminating information about ACDs in the 1990s to seeking strategies to better explain human behaviour consistent or inconsistent with participating in ACP in the 2000s was clearly noted in the literature. The literature review raised the need to expand

the understanding of autonomy, as it can be challenged in social contexts, within economic rationalism, within the context of standardisation, and in empowerment.

Nurses are often identified as advocates and communicators on behalf of individuals who are unaware, unsure, uncomfortable, and unable to express end-of-life care wishes. However, it is not surprising that the ACP programs facilitated by nurses have not always been successful, given the lack of knowledge, skills, time, involvement and commitment reported by nurses. The emerging roles and scope of practice for nurses in ACP and ACDs are debated with only a minor amount of scientific research evidence produced by nurses themselves.

The literature reviewed in this chapter has established the essential knowledge to better understand the phenomenon of ACP worldwide. However, there were gaps noted which require further investigation. A plethora of American literature is available with regard to ACP and ACDs. Nevertheless, it is worth investigating how ACP and ACDs are practised in the Australian health-care context, as the findings and implications revealed in the USA setting indicated that a new approach to ACP was unavoidable. Given that there is an assumption that ACP will promote a dignified death, the gaps found in the documented outcomes of ACP and ACDs justify the need for investigating what people have achieved through ACP. The attempts to understand what individuals or family members experience with ACP and documentation of ACDs were few in the literature. Whilst the relentless efforts to increase the documentation of ACDs should be acknowledged, there has been a failure to build a scientific knowledge to understand how ACP was accepted by older people, their family members and nurses. It is disappointing that nurses have been invisible and silent in the practice and debate of ACP. It is necessary, however, to examine to what extent the nursing profession is involved in ACP currently and what the scope of nursing practice is for the future.

It is clear that the time is overdue for serious debate about ACP and the scope of nursing practice in Australia. While ACP may not be immediately relevant for many patients with reversible illness or injury, it will become increasingly more important and relevant as our population ages. Hence, this study seeks to establish scientific evidence for illumination on the ACP debate.

In the following chapter, the researcher discusses the case study as a research methodology, the theoretical perspective of the study, the rationale for the methodological decisions made, and the methods employed to address the research questions.

## Chapter 3

### Research Methodology

#### Introduction

In the previous chapter, the literature review established the existing body of knowledge in relation to ACP, ACDs and associated issues. The review highlighted the gaps in the studies drawn from various disciplines and yielded interesting discussion relevant to nurses and current nursing practice. In this chapter, the researcher discusses the case study as a research methodology and outlines the methods undertaken to investigate the phenomenon of ACP and to answer the research questions. The chapter concludes with the processes and techniques used in the analysis of data.

According to Yin (1989), as a research endeavour, the case study contributes “uniquely to our knowledge of individual, organisational, social and political phenomena” (p. 14). Understanding the nature of case-study research should commence with exploring definitions of case-study research.

#### 3.1 Definitions of case-study research

Stake (1994) defined the case study as both the process of learning about the case and the product of our learning. However, case study has a variety of meanings within both research and clinical contexts (Elliot, 2003). There are arguments about the concept of ‘case’; the term itself is seen as ambiguous (Kemmis, 1980 in Stake, 1994). Hence one needs to ask what is a **case**? According to Gillham (2000, p. 1), a case can be “an individual, a group such as a family or a class; it can be an institution such as a school or a factory; it can be a large-scale community such as a town, an industry, or a profession”. Yin (2003a) added that the case can be some event or entity that is less well defined than a single individual, for example, decisions, programs, the implementation process, and organisational change. A case **study** is one which investigates an individual, a group, and a community to answer specific research questions and

which seeks a range of different kinds of evidence, which is there in the case setting, and which has to be abstracted and collated to get the best possible answers to the research questions (Gillham, 2000).

The term ‘*case study*’ refers to the study of a selected contemporary phenomenon to provide an in-depth description of essential dimensions and processes of the phenomenon (LoBiondo-Wood & Haber, 1994; Schneider et al., 2003). For the purpose of this study, the researcher adopts Yin’s (2003b) definition. Yin (2003b, p. 13) defines a case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident”.

What is as important as understanding the nature of the case study is that gaining the best possible explanations of phenomena depends on defining ‘the case’ well (Patton, 1990; Yin, 1989). As suggested by Stake (1994), a proper selection of cases should be the first priority of the case-study researcher. In the current study, ‘the case’ is the ‘phenomenon of advance care planning’. The essential dimensions of the phenomenon include the implementation of ACP and utilisation of ACDs in RACFs. The phenomenon on the table is ACP. The researcher intended to improve the understanding of how ACP was implemented and how it was accepted by the people involved in RACFs. The researcher was also interested in the process of ACP implemented by a CNC accompanying documentation of ACDs.

### 3.2 History of case-study research

The conceptual origin of case studies is “social sciences; including the traditional disciplines of psychology, sociology, history, anthropology, political science and economics” (Talbot, 1995, p. 441). The case-study method is not a new use of research. Talbot (1995, p. 427) located the use of the case-study method with “a small number of people in some of the most influential theories”, such as Freud’s theory of ego development and Piaget’s child learning.

In the health sciences, case studies have been used “primarily for teaching where there has been a clear need to confront the idiosyncrasy of individual instances” (LoBiondo-Wood & Haber, 1994, p. 274). As a result, case-study methodology has suffered somewhat because “the

intrinsic nature of the study of a particular case is considered not as important as studies to obtain generalisations pertaining to a population of cases” (Stake, 1994, p. 238).

Given that case-study research has only recently come into its own (Gillham, 2000) and “the skills for conducting good case studies have not yet been defined” (Yin, 2003b, p. 11), in the past, case-study research has been little honoured. Many social scientists criticised the case study; arguing it is a typification of cases, an exploration leading to bigger studies to generalise, or an occasional early step in theory-building. However, at other times, case studies have generally been utilized and developed where there has been no clear vision of an appropriate theoretical base from which to operate and where there has been a need to supplement inadequate and poorly conducted quantitative work (Yuen, 1991).

### 3.3 Case-study research in nursing

Talbot (1995, p. 10) points out that case studies have played “a key role in establishing scientifically tested and measured knowledge in nursing since the 1920s in America”. Case studies were published in the *American Journal of Nursing (AJN)* in the 1920s and they were regularly featured by the 1930s. Since then, case studies which appeared in nursing literature have described “nursing ethics, political action in nursing, and the discipline of nursing through sharing paradigm cases, nurse–patient stories and narrative accounts” (LoBiondo-Wood & Haber, 1994, p. 274; Moeller, 2006). However, case studies in these references did not contain a systematic approach and the methodological rigour required to be classified as research and have failed in the endeavour to develop case-study research methodology in the nursing context.

Although case-study research has been endorsed by nurses (Burns and Grove, 1995; Munro, 1992; Sterling & McNally, 1992), there are few examples of nursing studies that use case-study research (LoBiondo-Wood & Haber, 1994). Yin (1989) stated that the case study allows “an investigation to retain the holistic and meaningful characteristics of real-life events such as individual life cycles, organisational and managerial processes, neighbourhood change, international relations, and the maturation of industries” (p. 14). An example of a nursing qualitative case-study research is the work of Beil-Hildebran (2006). She examined the actual

labour processes and the concrete experiences of health-care employees including nurses, one student nurse, directorates of nursing, chief executive officers, and chief medical executives behind the 'Management by walking about' approach in a German hospital (p. v). The author collected data from a six-month field study of the nursing division, using participant observation and semi-structured interviews. Her case-study approach was praised, as the data highlighted critical text that was socially constituted beyond the discourse of texts concerning the wider context and organisational processes. Bartlett (2007) also justified the case-study method in her study of the phenomenon of social exclusion and men with dementia in nursing homes. She ensured the 'voices of people with dementia' were studied holistically in the context of cultural dynamics and practices, using three to five additional unstructured interviews with the participant, semi-structured interviews with a relative and key workers, analysis of particular documents and environmental observations.

The above examples demonstrate the potential range of ways in which the case-study approach might be used in nursing. Case-study research offers another 'qualitative avenue for nursing in understanding the implications of changes in the health-care industry on nursing practice' (LoBiondo-Wood & Haber, 1994, p. 274; Talbot, 1995, p. 456).

### **3.4 Advantages and disadvantages of case-study research**

Gillham (2000) argued that the naturalistic style of case-study research makes it particularly appropriate to study human phenomena, and what it means to be human in the real world 'as it happens'. However, case-study research has been stereotyped as a weak method. One of the contributing factors to the stereotype may be that case study is used as a teaching tool which does not involve the rigour and systematic research approach (Yin, 2003b). This stereotype is derived from the fact that people have confused case-study teaching with case-study research. "In teaching, case-study materials may be deliberately altered to demonstrate a particular point more effectively. In research, any such step would be strictly forbidden. Every case-study investigator must work hard to report all evidence fairly" (Yin, 2003b, p. 10).

Another contributing factor to the stereotype is derived from the hierarchical view on various research strategies. Yin (2003a) argued the view that many social scientists hold, in that



explorative studies are of less value than descriptive and explanatory studies in the hierarchy. In other words, case studies are only appropriate for the exploratory phase of an investigation and only a preliminary research strategy and cannot be used to describe or test propositions. However, Yin (2003a) provided the examples of the best and famous case studies that have been both explanatory and descriptive. He also clearly pointed out that research strategies should be chosen based on the research questions, the extent of control over the events, and the degree of focus on contemporary, not solely by their place in the hierarchy.

Gillham (2000, p. 7) outlined the problems and challenges of using case-study research. Perhaps the major issue is “the greater concern of naturalistic case-study research with subjectivity; with phenomenological meaning”. In the case study, the investigator comes to know what has happened partly in terms of what others reveal as their experience. The case researcher emerges from one social experience to interpret another. This does not mean that the researcher excludes the objective (what people do, what records show, and so on), but that the researcher seeks the qualitative element; how people understand themselves, or their setting – what lies behind the more objective evidence. Nor does it mean that the researcher ignores objective results (for example, reading standards in a school, staff turnover in a nursing home) but that the researcher seeks to find the underlying reasons – in people’s feelings or perceptions, or their experiences of what is going on. This concern with process (leading to the outcomes or ‘results’) will be the key to understanding what needs to be done to change things (Gillham, 2000, p. 7).

A case study is the intensive study of one person, group, institution or other social unit (Lobiondo-Wood and Haber, 1994; Polit & Hungler, 1991, 1993), which is limited to a small number of subjects; the results are not readily generalised to other populations (Crookes & Davies, 1998, p. 132; Talbot, 1995). However, case-study research is preferred as its unique strength is in its ability to deal with a full variety of evidence – documents, artefacts, interviews, and observations – beyond what might be available in a conventional historical study. In addition, one of the advantages of case studies is the detailed level of analysis that results when research is confined to a small number of subjects (Talbot, 1995). A complete analysis can provide evidence for the relationships among variables and the depth of the case descriptions or explorations as they are written. The cases provide sufficient details for the reader to “grasp

the idiosyncrasies of the phenomenon and stimulate additional research questions in an area of study” (Talbot, 1995, p. 234, 457).

As Hammersley (1984), Polit and Hungler (1995) and Strauss (1987) suggested, the case-study approach has the unique quality of being an open system approach to study a whole system, not just a part of it. This has caused the dilemma of where to begin and end without risking the exclusion of important events and salient features. However, it is the open system approach that provides an opportunity to reformulate the problem and revise the design as the research is being conducted. By being non-standardised, the inquiry can more readily be directed on the basis of the data to more fruitful areas of investigation. In addition, the case-study approach allows the establishment of relationship between the observed and the researcher to elicit valuable information. This information can be incorporated into the development of formative evaluation. The more direct relationship with daily experience means that extraneous questions and irrelevant materials can also be avoided (Yuen, 1991).

Another important strength of case-study research is the analysis of contemporary phenomena investigated within their ‘real-life’ context (Yin, 2003a). There are at least two philosophical bases to support the ‘real-life’ context. First, human behaviour, thoughts and feelings are partly determined by their context. If you want to understand people in real life, you have to study them in their context and in the way they operate. Second, “how people behave, feel and think can only be understood if you get to know their world and what they are trying to do in it” (Gillham, 2000, p. 11). It is necessary to be clear about the philosophical base of the qualitative case-study research methods.

Perhaps the greatest concern has been over the lack of rigour of case-study research. The case-study investigator might be sloppy, not follow systematic procedures, or allow equivocal evidence or biased views to influence the direction of the findings and conclusions. Such lack of rigour is less likely to be present when using the other research methodologies – possibly because of the existence of numerous methodological texts providing investigators with specific procedures to be followed. In contrast, few if any texts cover the case-study method in similar fashion (Yin, 2003b).

Despite all the stereotypes and negative criticisms about case-study research, case-study research continues to be used extensively in psychology, sociology, political science, social work (Gilgun, 1994) and community planning (Yin, 2003a).

### **3.5 Validity and generalisability of case-study research**

Validity and generalisability have been the major barriers in doing case-study research. Yin (2003b) suggested four tests to judge the quality of any given design; these include construct validity, internal validity, external validity, and reliability. These are more complex than the standard ‘validity’ and ‘reliability’.

“Internal validity” is only a concern for the causal (explanatory) case study, in which an investigator tries to determine whether event  $x$  led to event  $y$ . ‘Reliability’ aims to minimise the errors and biases in a study by doing the same case over again, not by replicating the results of one case by doing another case study (Yin, 2003b, p. 37). The reliability is regarded highly if a later investigator followed the same procedures as described by an earlier investigator and conducted the same case study all over again; the later investigator should arrive at the same findings and conclusions. The case-study research reported here uses an exploratory and descriptive design. For this reason the following discussion focuses on “construct validity”, and “external validity”.

“Construct validity” is about ‘establishing correct operational measures for the concepts being studied’ (Yin, 2003b, p. 34). Most case-study researchers are concerned about the validity of their communication. There is an expectation that the meanings of a situation, observation, reporting and reading will have a certain correspondence. Meanings generated by the investigator during data collection may not transfer to the reader as intended, but entail the uniqueness of the reader (Stake, 1994). The validity of observational accounts in particular relies heavily on the truthful and systematic representation of the meanings collected. This is not an easy task, and observational research is therefore particularly demanding of the individual researcher (Mays & Pope, 1995). Various strategies are proposed to increase construct validity in case-study research.

The strategy used in this case study was triangulation, as Crookes and Davies (1998), and Stake (1994) draw attention to redundant data-gathering and procedural challenges to explanations. Triangulation could accommodate at least two different meanings, according to Denzin (1978). One is triangulation by using multiple perceptions. This is described as data-source triangulation by Denzin (1978), which means using two different key people to collect data about the same topic. The other triangulation is described as method triangulation, which means using more than one method of data collection. This triangulation by using multiple sources of evidence is supported by Yin (2003b). Yin (1994, p. 69) proposes that the researcher should ask “the same question of different sources of evidence and if all sources point to the same answer”, the researcher has successfully triangulated the data. The researcher employed both data-source triangulation by collecting data from the residents, family members, and RNs. By using method triangulation with multiple sources of data (participant observation, field notes, interviews, and document analysis) it was believed that the researcher would substantiate or negate findings from the various data sources and therefore increase the likelihood of achieving construction of validity in investigating the phenomenon of ACP in RACFs.

Another approach taken by the researcher for triangulation was that interview data were validated through observations and conversations with the residents, family members, nursing staff, the physiotherapists, and other visitors like GPs. It is believed that the informal interactions that occurred during the observation period provided time to build trusting relationships and contributed to the depth of the data collected. Several days following each interview, the researcher informally reviewed the interview data at the participants’ request and agreement using the exact phrases as identified by them. Participants were able to clarify and expand upon thoughts they might not have articulated at the time of the interview. Responses lacking depth and substance were probed, based upon regular observations of participants.

Although Meier and Pugh (1986) questioned whether or not the goal of generalisation was applicable to all research, Yin (2003a; 2003b) took up the issue of external validity which he referred to as generalisability. The question of whether or not a study’s findings are generalisable beyond the immediate case study has been a second concern in relation to case-study research as they provide little basis for scientific generalisation.

Yin (2003a, 2003b) points out that the possibility of generalisation from the result of a single case study is as rare as it can be from a single experimental study. It is important to note that scientific facts are often based on multiple sets of experiments and multiple case studies are required to produce similar effects. When one asks ‘how can you generalise from a single case?’, the answer is that case studies, like experiments, are generalisable to theoretical propositions and not to populations or the universe. In this sense, the case study, like the experiment, does not represent a ‘sample’, and in doing a case study, the goal is to expand and generalise theories (analytic generalisation) and not to enumerate frequencies (statistical generalisation). Generalisation of the findings of case-study research in the statistical sense is rarely appropriate, however, the development of theoretical generalisations or propositions is important (Crookes & Davies, 1998). In this case study, the researcher did not attempt to statistically generalise the findings from the current case study. However, it would be treated as a sample from a larger universe and analytical generalisation attempted and thus there is a possibility of statistical generalisation in future research.

Stake (1994) and Schneider et al. (2003) warn that the case study approach is observational and responsive to the context, and is examined in its own right without regard for generalisation to the whole population, and damage may occur when the commitment to generalise or create theory runs so strong that researchers’ attention is drawn away from features important for understanding the case itself. Stake (1994) suggested that case-study results were generalisable in that the information given allowed readers to decide whether the case was similar to theirs.

It is advisable to apply a theoretical framework to the data to guide its analysis in case-study research to improve the generalisability of theoretical propositions (Yin, 1994). A theoretical framework provides the necessary structure within which to locate and analyse the data. Without a framework, “... case studies can easily degenerate into anecdotal story-telling” (Glen & Waddington, 1998, p. 286). Therefore, the researcher has taken Yin’s advice and a theoretical framework developed by Andersen (1978) was adopted. The theoretical framework in Nursing Activity Models and Nursing Roles and Functions Models is depicted and discussed in Chapter 4.

Whilst it is recognised that the process of data collection for a case study is time-consuming, the quality of data collected would be judged by the construct and external validity by using strategies suggested above.

### 3.6 Rationale for the choice of case-study research and components

Given the nature of the setting and subject matter, it was decided to base the research on a single case-study design (Yin, 1989). The researcher used Yin's (2003b) recommendation for the case-study research. Case-study research was selected to investigate the phenomenon of ACP in RACFs as:

- it has not been rigorously researched, and
- the investigator has little control over the events, and
- the focus is on a contemporary phenomenon within some real-life context.

In identifying the answers to the research questions, a methodology is needed that would serve two purposes. First, it would provide systematic procedures for in-depth description of essential dimensions and processes of the contemporary phenomenon of ACP in RACFs. Second, it would provide information useful for exploring residents', family members', and RNs' experiences and perceptions in relation to ACP and ACDs.

The case study as a research method is also justified by several authors who defined the distinctive role of the case study in evaluation research (Patton, 1990; Yin, 1993). First, the case-study strategy should be used to "*explore*" those situations in which the intervention being evaluated has no clear, single set of outcomes (Yin, 1994, p, 15). In this study, the researcher explored the outcomes of ACP as an intervention program for older people and their family members in end-of-life decision-making processes in RACFs. Given that the research questions have not been investigated since the program was implemented, it was difficult to speculate what the outcomes would be. However, it was anticipated that the ACP program would generate multiple sets of outcomes, as it involved residents, family members, and nursing staff. The case study enabled the researcher to depict the whole picture of the outcomes of the program, as the study aimed to explore experiences of people involved in

ACP and ACDs.

Second, the application of the case study is encouraged when the study aims to “*describe*” an intervention and the real-life context in which it occurred (Yin, 1994, p, 15). The research project aimed to describe the implementation process of the ACP program in RACFs where the phenomenon of ACP has been occurring since 2001. The case-study approach allowed the researcher to be able to observe and describe the implementation of the program and the outcomes.

In summary, a case study of the phenomenon of ACP and people’s experiences with the processes of ACP in health services cannot rely on a single data -collection method, but should use multiple sources of evidence to enrich the understanding of the phenomenon (Yin, 1993). As a result, a single case-study approach was utilised to investigate the phenomenon of the practice of ACP in RACFs in Australia.

Yin (2003b, p. 21) strongly suggested that a case-study research design should include “five components”. In the following, the researcher describes how this case-study research was designed including Yin’s five components. The first component identified by Yin (2003b) is ‘study questions’. In this study the questions were:

- How and why are ACP and the use of ACDs implemented by the CNC in RACFs?
- What are the outcomes of ACP for residents, family members, and RNs?
- How do residents, family members, and RNs perceive their experience with ACP in RACFs?
- How is the scope of practice perceived by the CNC and the RNs in ACP in RACFs?

The second component identified by Yin (2003b) relates to the need to articulate study propositions. In this study, the study propositions were:

- Implementation and utilisation of the ACP service by the CNC in RACFs will promote the autonomy of residents and maintain dignity of the older person
- Implementation and utilisation of the ACP service by the CNC in RACFs will develop and expand the scope of practice of the CNC and the RNs.

Unit(s) of analysis comprise the third component of a case-study research design. This component is related to the fundamental question of how to define what the ‘case’ is. According to Yin (2003b, p. 22), a case is “a problem that has plagued many investigators at the outset of case studies. The ‘unit of analysis’ is an aggregation and component that constitutes and represents the phenomenon and that requires analysis”. In the context of this study, the ‘case’ was defined as the phenomenon of ‘ACP in RACFs’. The units of analysis were the ‘implementation process of ACP’, ‘outcomes of ACP’, ‘experience of individual in the context with ACP’, and ‘scope of practice of nurses in ACP’.

Yin (2003b) suggested ‘the logic linking the data to the propositions’ as the fourth component of a case-study research. Yin (2003b) emphasised the importance of linking data to propositions, although there was no precisely defined way to achieve this. He adopted the idea of pattern-matching described by Campbell (1975, cited in Yin, 2003b). ‘Pattern-matching’ enables the researcher to relate the data collected to the propositions. This component of research design was important for the researcher, as it helped the researcher to focus on the study aims and questions while analysing and interpreting the data. For example, one of the findings from the data was that the residents with ACDs were less likely to be hospitalised with regard to their wishes, which could then be linked to one of the propositions, that is, to promote autonomy of the individuals.

The last component of a case-study design is ‘the criteria for interpreting the findings’. This component is about how close a match in pattern has to be in order to be considered as a match. Yin (2003b) admits that there are no precise criteria set aside for interpreting the data collected for their matching ability in case studies. The researcher has taken Campbell’s (1975 cited in Yin, 2003b) suggestion that the findings can be interpreted in terms of comparing at least two rival propositions. This component was included by taking examples, where possible and/or available, that may contrast with the propositions. For example, the researcher



illustrated the outcomes or experiences of individuals who participated in ACP and who did not.

For case-study research, theory development (analytic generalisation) is essential in the research design phase in order to provide strong guidance in determining what data to collect and the strategies for analysing the data (Yin, 2003a). A well-designed research including the above five components helps the researcher generate the theory of how the ACP was implemented and why the implementation of ACP succeeded or failed in RACFs. It will also show why and how the scope of practice of the CNC and the RNs has been developed in cases of successful implementation of ACP.

To accomplish these aims, the methodology should provide a comfortable face-to-face relationship between the potential participants and the researcher. It should allow a choice of techniques and procedures for the collection of useful information. It should permit an ongoing analysis of the environmental factors and be as culturally unbiased as possible. In a face-to-face relationship, the researcher can gain more thorough understanding and a better sense of knowing the participants. An awareness of the participants' world can therefore be gathered. The participants' interests and values would provide a pivotal point guiding the collection of data and the interpretation of the social setting. Techniques such as observation and interviewing often provide crucial data about the otherwise intangible affective experiences of the residents, family members, and nurses (Yuen, 1991).

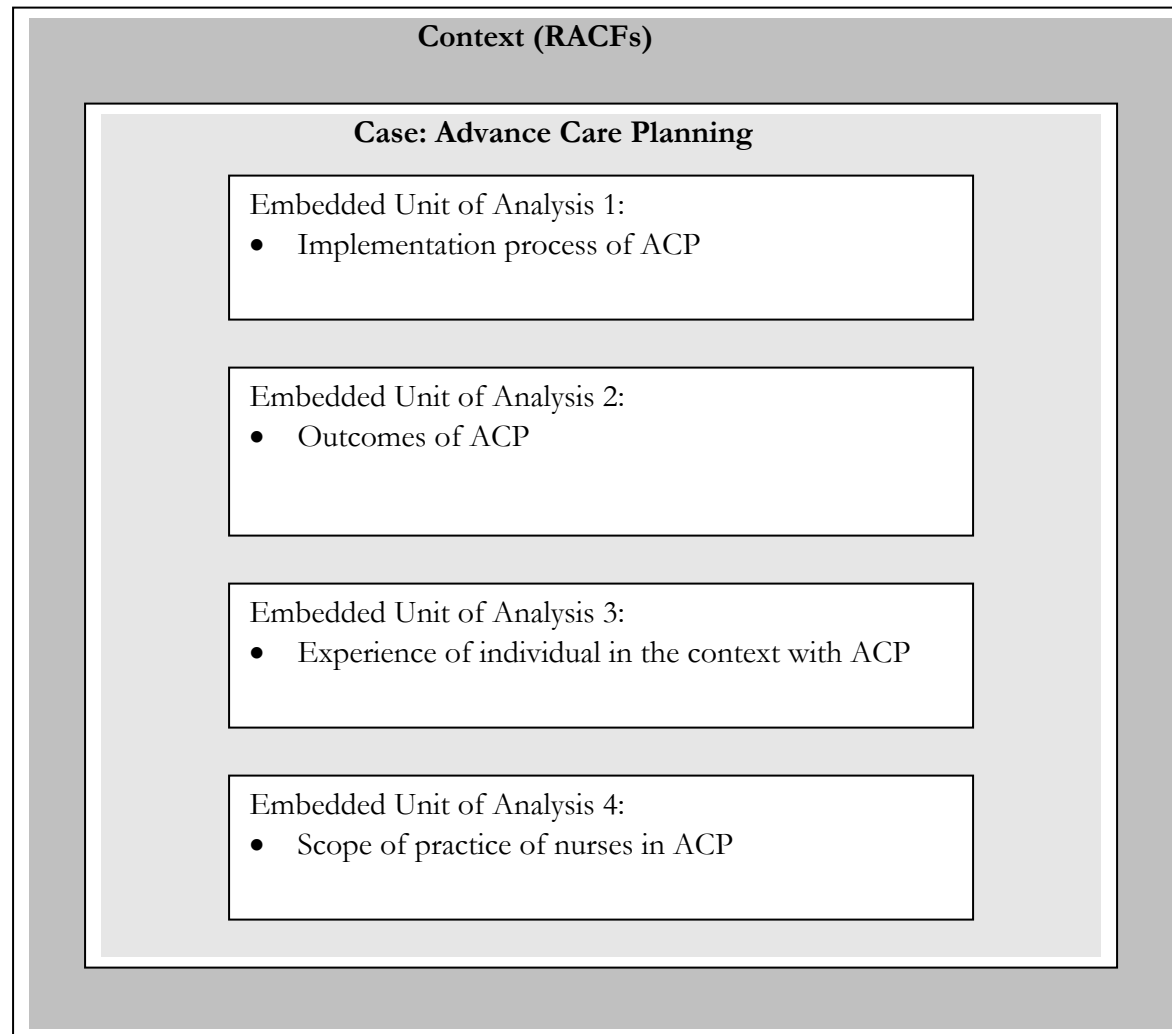
### **3.7 Case-study research design**

The approach to this study is qualitative in its philosophical stance, although the triangulation of methods enables use of “the full range of data-collection strategies – interviews, field notes, participant observation, and contemporary documents” (Bergen & While, 2000, in Schneider et al., 2003, p. 35). As with other qualitative approaches, the analysis of case-study data commonly uses “a constant comparative approach” (Hewitt-Taylor, 2002 in Schneider et al., 2003, p. 35).

Yin (2003b) discussed four types of designs for case studies that are relevant, following a 2 x 2 matrix. The first pair consists of single-case and multiple-case designs. The second pair is based on a unitary unit or multiple units of analysis. A single case study with multiple units of analysis, which is a type 2 case study design in Yin's classification- was chosen as Yin (2003b) recommended this when the case is an unusual or rare case, the critical case, and revelatory case. Considering that the ACP program was the first and only project in NSW at that time, a single case study is methodologically well justified. Multiple units of analysis provided the researcher with compelling and robust evidence to test the propositions and to produce analytic generalisation of the phenomenon of ACP in RACFs. The final research design for this case study is depicted in Figure 3 – 1.

In summary, a case study of the phenomenon of the ACP program and people's experiences with the processes embedded in ACP in health services cannot rely on a single data-collection method, but use multiple sources of evidence to enrich the understanding of the phenomenon (Yin, 1993). Data collection in the study proposed included document analysis, and semi-structured interviews with study participants within an ongoing context of participant observation. The various data-collection techniques used in the current case study are now discussed.

**Figure 3 – 1. A case-study research design: A single case study of the phenomenon of ACP with multiple units of analysis**



### 3.8 Research setting

Stake (1994) pointed out that the primary criterion in choosing persons, places and events to observe is dependent on the opportunity to learn about the phenomenon. He also emphasised the importance of hospitality from the people in the field, as the time is short and too little can be learned from inhospitable people. As the context is recognised to be part of the phenomena in the case study (Yin, 1993) the current case-study research was conducted where the phenomena of ACP and ACDs could be observed and where the researcher could have direct contact with people who were involved in the ACP program.

The ACP program and the use of ACDs in RACFs in which a CNC was involved were initiated as part of the Chronic & Complex Care Program Project in NSW, Australia in 2001. This project was supported by a regional Area Health Service (AHS), with funds sought from the Department of Health NSW, and hence it was the expert CNC and the context of her practice that were the focus of the study. The ACP program was aimed at those residents receiving high-level residential care, residing within the northern sector of the regional AHS. This area includes two teaching hospitals (combined with about 710 public hospital beds), 20 high-care facilities providing a total of 1,335 high-level care beds for the 65 years and over population of about 44,000 people in four municipalities. Three RACFs at different locations in the AHS were selected on the base of accessibility, timing, their involvement in the ACP program, and, more importantly, their willingness to participate in the study. Amen, Christ Heaven, and Evergreen RACFs are pseudonyms to represent three research settings.

### 3.9 Data collection methods

The justification for using a case study for this research lies in its capacity to allow the researcher to collect data in a natural setting using a range of data collection methods when multiple and diverse outcomes are expected. The use of multiple sources of evidence enriched the understanding of the phenomena (Stake, 1994; Yin, 1993). The case-study researcher has to decide the extent and the complexities of the case. These decisions were made by the researcher based on the research questions and the determination on the saturation of the data collected to answer the research questions (Stake, 1994).

According to Gillham (2000), being open-minded as much as possible is the key to success in data collection in case-study research as we, human beings, can assume that the familiarity developed by understanding in one context can easily blind us and close our minds in another context. Gillham (2000) and Yin (1989) suggested that in the case study, the researcher should look for different kinds of evidence: what people say, what you see them doing, what they make or produce, what documents and records show. In the end, all of this evidence needs to be woven into a narrative account presenting what Yin (1989) called a chain of evidence, which means that each key element or link in the researcher's account is supported by or related to evidence of different kinds (Gillham, 2000).

Data collection in this case study included the following. Time frames and processes to achieve in each step are depicted in Appendix 1.

- Participant observation: Part 1 of the observation involved participant observation of the roles and functions of the CNC in ACP. Part 2 of the observation incorporated participant observations of residents, families, and RNs in relation to ACP and ACD in RACFs where the CNC provided consultancy on the development and implementation of ACP and ACDs.
- Field notes included any events, situations, conversations, thoughts, opinions, observations and impressions in relation to the study aims and research questions.
- Semi-structured interviews with residents, family members and RNs re ACP and ACDs.
- Document analysis re ACP and ACDs and demographic information pertaining to residents.

Prior to commencement of the data collection, ethics clearances from the University of Newcastle and the regional Area Health Service (AHS) were achieved. Permission to access the RACFs in order to undertake the study was sought from the relevant RACF ethics committees or designated authorities through the DONs in each facility. The researcher was invited to present her research proposal to the DONs in the RACFs in the Area at their bimonthly meeting. The researcher presented the emergence of ACP in the USA, the benefits of and

difficulties with ACP and ACDs, the practice of ACP in RACFs in Australia, and the research proposal. The DONs were invited to participate in the research project, and the information letter (see Appendix 2) and permission to enter the premise (see Appendix 3) was distributed at the end of the sessions. The researcher presented twice, once in February and again in April, 2006 for those who could not attend the first meeting.

### 3.9.1 Participant observation

Participant observation is widely accepted as a research method used to understand contexts (Patton, 1990; Wiseman & Aron, 1970). Observation methods used in the social sciences involve the systematic, detailed observation of behaviour and talk; watching and recording what people do and say (Mays & Pope, 1995). The primary mode of data collection in this study was participant observation of every encounter between the ACP program manager and residents and their family members in the ACP program. The researcher was also engaged in observation of formal and informal discussions about end-of-life treatment options. This provided the researcher with an opportunity to examine the advance decision-making process and to understand the scope of nursing in ACP as it took place within the context of the nurse – patient relationship.

However, observation in research can be time-consuming, because the scenes that are relevant to research may not occur at the researcher's convenience (Patton, 1990; Wiseman & Aron, 1970). Another setback could be the use of the researcher, as an instrument as it requires "an acceptance that the researcher is part of the study" (Crookes & Davies, 1998, p. 153; Streubert & Carpenter, 1999). The researcher as an instrument may be the most troublesome problem in observation, because of the possibility of researcher bias that can contaminate findings. There may be accounts that people give of their actions caused by factors such as the wish to present themselves in a good light, differences in recall, selectivity, and the influences of the roles they occupy (Mays & Pope, 1995; Talbot, 1995). According to Streubert and Carpenter (1999), it is unlikely, that the introduction of an unknown individual would not change the context of the relationships and activities observed, and the researcher's prolonged presence should maximise the possibility of capturing relevant events in the setting and have the effect of minimising her/his intrusion.

Another difficulty with participant observation is that the researcher has to have an understanding of what is happening and how it is happening in the context as he/she is the interpreter of various aspects of phenomena (Streubert & Carpenter, 1999). The researcher has work experience in a hospital setting where majority of the beds are occupied by people aged 65 and over, in a day-care centre for older people with dementia in a community and in a nursing-home setting in Australia. Therefore, use of participant observation for data collection is justified, given that the researcher has some understanding of nursing practice in looking after older people and of the meaning or interpretation of what is happening.

Mays and Pope (1995) warn about the risk of 'going native' by becoming so immersed in the group culture that the research agenda is lost, or that it becomes extremely difficult or emotionally draining to exit the field and conclude the data collection. The researcher used strategies to prevent this happening. By limiting the time spent in one setting and rotating the observation fields randomly and regularly, the researcher was able to keep focused and maintain the distance that was required to collect meaningful data in the field. The researcher stayed in one setting long enough to build a good relationship but then moved into another setting before the researcher and the people in the setting became too close and felt that the researcher was a member of the staff in that particular setting. It was entirely the researcher's intuition and decision when to leave the field and for how long, and when to come back to the field.

The advantages of observation outweigh the setbacks as a data-collection method. An important advantage of observation is that it can help to overcome the discrepancy between what people say they do and what they actually do. Observation also allows the researcher to capture the event that only an outsider or newcomer to the scene would have considered noteworthy. For these reasons, observational methods are particularly well suited to the study of how the people within them perform their functions in programs and organisations. It may also uncover behaviours or routines of which the participants themselves may be unaware (Mays & Pope, 1995).

The degree of participation varies according to the nature of the setting and the research questions (Mays & Pope, 1995; Morse & Field, 1995). According to Streubert and Carpenter (1999), generally, four types of participant observation are discussed in the literature. One type of participant observation is the observer as participant. In this situation, the predominant activity of the researcher is to observe and potentially to interview. The majority of the researcher's time is spent in observation, however, to fit into the setting and minimise the impact on the environment being studied, the researcher may engage in some activities with the participants (Mays & Pope 1995; Morse & Field, 1995; Streubert & Carpenter, 1999). The researcher endeavoured not to influence the interactions of others by her presence, although she may have needed to participate in activities to try to more closely experience the meaning they might have to the people involved.

The researcher was engaged in participant observation in three RACFs over a period of six months, with the objective of exploring the *context* of RACFs where the ACP program and ACDs were part of practice, and the *process* of ACP and the use of ACDs, in particular how residents, family members and RNs perceived their experiences with the ACP and ACDs. All observations relevant to ACP and ACDs in the RACF, verbal and nonverbal interactions with residents and family, and nursing care activities were recorded daily as computerised field notes, using a strategy developed by Spradley (1980). Spradley's guidelines for setting dimensions to the descriptive aspects of the participant observation process were used with another addition. These guidelines sought the following information about:

- a) space: layout of the physical setting
- b) actors: the coded names and relevant details of the people involved
- c) activities: the various activities of the actors
- d) objectivities: physical elements
- e) acts: specific individual actions
- f) events: particular occasions
- g) time: the sequence of events
- h) goals: what the actors are attempting to accomplish
- i) feelings: emotions in particular contexts
- j) relevant impact: why the researcher thought the situation was relevant.



Points a) – j) reflect Spradley’s original guidelines, but a tenth point was added by the researcher as a means of giving essential information about an explanation of why the scenario was observed and recorded.

The researcher observed the interaction between the residents – families – RNs in each facility in order to grasp any events that may be relevant to the study aims. The task of the researcher was also to focus on what and how the expressed wishes of residents were followed in everyday events in RACFs. The researcher was also available to listen to the residents, families and nursing staff whenever they wished like to share their concerns, feelings, worries, and thoughts in relation to ACP and ACDs.

The foci of participant observation were answers to the following questions:

- How do the CNC and/or residents, families, and RNs initiate, sustain, inform, and integrate ACP into nursing care?
- What leads to the effective integration of the residents’ ACDs into nursing care plans?
- How do residents, family members, and nurses respond and interact with regard to ACP and ACDs?
- How do residents, family members, and nurses communicate with regard to ACP and ACDs?

The researcher undertook strategies to address ethical concerns for individuals who might be exposed to observation. First of all, the researcher was granted permission to enter the facility from the DON in each facility. Second, permission to be present while the CNC was visiting a resident or family member was sought. Third, personnel in the research field were informed and given the opportunity to express their wish to be or not to be observed. In addition, in one facility, all residents, family members, and staff were invited to the presentation of research project after obtaining ethics approval from each RACF. Therefore, prior to the commencement of participant observation, all the personnel in RACFs were aware of the research project. In the other two facilities, the DONs did not require formal presentations to be given by the researcher, but did communicate with the residents and families in family

meetings and the staff through the communication books. The researcher was diligent in introducing herself and explaining the research project to everyone she encountered while observing in the facilities. An announcement letter for non-participants (Appendix 4) describing the research project including the complaint process, if needed, was made available to them on the noticeboards for staff, families and visitors in each facility. No residents, families or staff members made a complaint or raised an issue with regard to the manner in which the researcher conducted the study.

#### 3.9.1.1 Participant observation: Part 1 – CNC

The researcher was engaged in participant observation for over six months. In the first two to four weeks, however, this primarily involved the researcher in understanding the contemporary nature of ACP. She shadowed the only experienced ACP Program Manager, a CNC who worked in an Area Health Service and provided a service to the RACFs in NSW, Australia in the same geographical location. The CNC consulted with RACFs proposed as study sites for observation with regard to ACP.

The observation of the CNC was undertaken in order to understand what her roles were and what was involved in the ACP process. This period of observation also allowed the researcher to become familiar with the formal processes and documents before she initiated observation of ACP in each RACF. In principle, support for this period of observation was obtained in an informal conversation with the CNC. Formal consent was sought from the CNC before proceeding with this observation through the formal letter of invitation (see Appendix 6) and the consent form (see Appendix 7).

The residents whom the CNC was likely to formally visit, and any family member who wished to be present during this initial visit, were given an opportunity to express their wishes to have or not to have the researcher present. The researcher was contacted by the CNC and joined her on visits to her clients only when consent from the residents and their families was obtained. The observations during this initial visit could involve not only the CNC, residents, family members but also nursing staff. Verbal consent to observe the nurses in the immediate practice setting and scope of their practice in relation to ACP in the RACF was sought. It was

left to the DON and the CNC to determine whether or not staff members' consented to the presence of the researcher. All staff had knowledge of the research project as a result of ethics clearance processes within the RACFs.

#### 3.9.1.2 Participant observation: Part 2 – RACFs

On entry to the field of RACFs the researcher observed the interactions between the residents – families – RNs, those either currently involved in or anticipating involvement in ACP in each facility, in order to gather insight into any events that may be relevant to the study aims. The task of the researcher was to focus on how the ACP program was practised in the RACFs and how it was being experienced by the participants.

The observations took a maximum eight hours per day in RACFs with particular reference to the ACP and ACDs. The time in RACFs for observations took approximately four to five months, depending on the level of activity in each context and the time it took to achieve saturation of the data. Saturation was determined by the researcher's judgement on the nature and extent of the use of ACP and ACDs in the respective RACFs and in relation to the value of the data collected with regard to the aims of the study.

All recorded comments relevant to ACP and ACDs in both observations of the expert CNC and her clients, and in the context of RACFs, derived from verbal and nonverbal interactions with residents and family members, and nursing care activities. Details of observations were documented in a journal completed daily. The latter constituted the researcher's field notes. The focus of participant observation was guided by following questions.

#### 3.9.2 Field notes

The crucial element in the mode of data collection through observation is the recording of comprehensive field notes (Taylor & Bogdan, 1984). According to Streubert and Carpenter (1999), field notes are the notations that qualitative researchers generally make to document observations. The data from observations are then organised and drawn together into a

cohesive whole. These notes become part of data analysis (Morse & Field, 1995; Streubert & Carpenter, 1999).

The subjective nature of field notes that record exactly what happened, including personal feelings and responses to the situations witnessed and the systematic recording of data are a crucial component of the process of analysing qualitative observational data (Crookes & Davies, 1998, p. 154; Mays & Pope, 1995). As it is impossible to record everything, this process is inevitably selective and relies heavily on the researcher, who in this study has taken a recommendation from Mays and Pope (1995) that the observations are systematically recorded and analysed, through the traditional field notes written during or immediately after the events occur, which may necessitate the development of memory skills and frequent trips to the lavatory to ‘write up’.

Another strategy taken by the researcher to maximise the advantage of field notes is the making of summaries every second week to plot the progression of thinking. Gillham (2000) pointed out how easy it is to lose focus and quality because of the complexity of the material in case-study research. Reviewing and summarising is essential to the discipline of case-study research. It needs to be done regularly and systematically – only in that way will the necessary level of control be maintained over the process. Therefore, the researcher took the four key points suggested by Gillham (2000, p. 24) to prepare a summary of:

- the different types of evidence uncovered
- immediate priorities for action
- revision of research aims and questions as needed
- thoughts about what might be happening, what this might be about, and how it might be explained.

The field notes included observations and impressions of the physical and social environment of the participants. The observation data recorded for the study also included drawings, copies of institutional literature, and maps. Field notes included records of informal conversations with consenting informants, residents, staff, and others. The researcher was well aware that, when recording field notes, it was important that researchers document what they have heard,

seen, thought, or experienced without upsetting the participants or missing significant actions (Streubert & Carpenter, 1999; Wiseman & Aron, 1970). Whenever possible, field notes were recorded immediately after a conversation ended in order to allow for the most accurate and clear retention of details. For similar reasons, observations were documented as soon after the event as possible. If this was not possible because of the need to focus on other issues, the researcher used shorthand notes to jot down a short outline of the issues she wished to elaborate on later in written notes. The researcher also included any contradictory or negative cases, the unusual, out-of-the-ordinary things which often reveal most about the setting or situation, as the search for negative cases during the data collection is an important facet of the analytic technique used in observational research (Mays & Pope, 1995).

### 3.9.3 Document analysis

Yin (2003a; 2003b) warned that the case-study researcher should not accept all documents as recordings of events that have taken place. All data collection techniques have potential flaws, and document analysis is criticised for assuming all kinds of documents contain the unmitigated truth. With this in mind, Yin (2003b) emphasised the importance of systematic searches for relevant documents, especially in undertaking case studies. Some of the advantages include that it can be reviewed repeatedly (stable), is not created as a result of the case study (unobtrusive), contains exact names, references, and details of an event (exact), and has a long span of time, many events, and many settings (broad coverage). Most of all, the importance of document use in this case study was in their “capacity to corroborate and augment evidence from other sources” (Yin, 2003b, p. 87). By paying attention to various documents in three different settings, the researcher was able to contrast, compare, and discuss the evidence collected from observations and interviews.

All available documentary material was subjected to scrutiny and that which was considered relevant to the study was copied and filed according to its source. All discussion/policy documents were included.

Information relating to the socio-demographic and health characteristics of consenting residents was collected by the DON from the residents and the family members for those who

were not able to consent due to cognitive impairment at the time of seeking consent for the interview. None of the residents or family members refused to supply this information, although they were given the opportunity to do so. A number of other documents (NSW Health Department Policy on end-of-life care decision-making, the Policy and Manuals outlining end-of-life care in each facility, the mission and value statements of the organisation, ACP and ACDs forms, documentation on Code of Ethics and Professional Conduct) were reviewed to analyse the formal operational ACP policies and practices.

The foci of document analysis were as follows:

- What formal and informal processes are available for end-of-life decision-making?
- How many residents have ACDs, NFR orders, or other end-of-life wishes documented?
- How many residents have a person responsible or an Enduring Guardian formally appointed in RACFs?
- How many residents have a surrogate decision-maker for end-of-life care issues?
- What methods do RACFs have to give voice to the wishes of vulnerable, dying, or incapacitated residents concerning life-sustaining interventions?
- What policy and/or manual do RACFs have to endorse ACP and ACDs?
- Marital status
- Medical prognosis
- Religion and attendance at religious services
- Frequency of contact with immediate family
- Identification of existing ACP and ACDs
- Organisational support systems for ACP and ACDs
- Spirituality: perceptions/views of end of life, diseases, and death issues
- Decision-making style/family involvement
- Willingness to plan/fears
- Financial issues, if any
- Any expressed preferences for CPR, Dialysis, tube feedings, surgeries, intravenous fluids, chemotherapy, antibiotics and hospitalisation.

### 3. 9. 4. Semi-structured open-ended interview

The nature of data collected in participant observation limits the conclusions about the process and impact of ACP in RACFs. Open-ended interviews provide study participants with the opportunity to fully explain their experience of the phenomena of interest (Mathers & Huang, 1998; Streubert & Carpenter, 1999). Interactions in semi-structured interview are incredibly rich and the data can produce extra-ordinary evidence that cannot be seen in structured interviews or questionnaire methodology (Morse & Field, 1995; Talbot, 1995).

Whilst the more structured interview schedules provide a means of classification and categorisation that is more reliable than non-scheduled interview techniques, there can be a disadvantage in the interviewer not being able to respond to any novel or meaningful answers, unless this can be achieved within the context of the next scheduled question. The participant might then assume that the interviewer was paying little attention to his/her replies, which could result in breakdown of rapport (Morse, 1991; Morse & Field, 1995).

For the above reasons, semi-structured, open-ended interviews were designed to elicit specific relevant information observed and to allow the residents, family members, and RNs an opportunity to express their experience with ACP and ACDs in each facility. Several strategies were employed to increase the validity of the data:

- The first two months provided time to build trusting relationships. Informal interactions occurred regularly prior to, and following interviews. This allowed the researcher to summarise data at the time of the interactions and feed it back to the participants for clarification, correction, and amplification. This technique was utilised during each interview.
- Timing interviews during less hectic periods, and allowing participants sufficient time to respond to questions, provided a relaxed, supportive atmosphere. The interview venues were also decided by the participants' preferences, either at the facility or in their own home.

- To facilitate understanding of the terms ACP and ACDs, the more colloquial terms of ‘end-of-life care decision-making’, ‘plan of treatment’ and ‘end-of-life care wishes’ were used.
- It was believed that in this study open-ended questions would result in a great deal of information and possibly draw out the reasons for the respondents’ pattern of thinking, which would in turn enhance the validity of results.
- It was also decided that the interviewer should probe further by asking the respondent such questions as ... what do you mean exactly by ...?’, or ‘... could you clarify that by giving some examples?’ This would resolve any lack of clarity or ambiguity in the response or enhance the response with the resultant elaboration.

#### 3.9.4.1 Participant selection criteria for interview

In contrast to quantitative research, a random sample was not selected in this qualitative case-study research. Rather, the researcher selected participants who were willing to participate in the study and who held key positions and had special knowledge of the phenomena under study (Morse & Field, 1995). As the name implies, convenience sampling invites the most readily available people who meet the inclusion criteria to act as subjects in a study (Ingleton, 1998; Nieswiadomy, 1993; Polit & Hungler, 1995). Although there are limitations with this approach in terms of its ability to generalise to a wider population, it is assumed to provide with rich data about the phenomena (Talbot, 1995).

As mentioned in the study aims, it is imperative to listen to what people who participated in ACP program perceive and experience with the program. Therefore, study participants consisted of the residents and their family members who have enrolled themselves in an ACP program, and the RNs who were involved in the program, and who spent varying amounts of time with the residents and families in the settings. The CNC, residents designated, family or friends, and RNs were the key stakeholders in the ACP process. They held the key to answers to the particular research questions; therefore they were included in interviews.



The residents who were invited to participate in the ACP program but had refused the offer were also included, as the study aimed to build up knowledge on what might interfere with ACD completion. However, potential participants who refused ACP also declined the invitation to participate in the study, hence the researcher was not able to investigate any further in this respect.

There was no attempt to include the residents who were not taking part in the ACP program. The senior managers in the main offices and administrative staff of each facility were also excluded, as the study did not seek for perspectives of the program from senior managerial and administrative levels. However, the DONs in each facility were included, as their involvement in the implementation of the ACP program and the use of ACDs was significantly related to research questions. It is often the Assistants in Nursing (AINs) in RACFs who provide residents with hands-on care for 24 hours. However, AINs were not included in the research project, as it was revealed that they were not heavily involved in implementation of the ACP and execution of ACDs but provided personal nursing care under the direct supervision of RNs.

The criteria for inclusion of each of the participants in the study sample are as follows:

#### **Expert CNC**

- Only known expert CNC for ACP in NSW, Australia who has also given consent to participate in the study.

#### **Residents who**

- enrol in ACP program in the regional AHS
- reside in a RACF
- are cognitively capable of consenting and understanding the research project (judged by the use of a tool within each facility to have Mini Mental Status Examination (MMSE) of 16/30 at least)
- speak English
- consent to be observed and interviewed.

**Family members who**

- have a family member enrolled in ACP program in the regional AHS
- have a family member in a RACF
- speak English
- are considered as a significant family member by the residents and/or themselves
- are in the opinion of the DON fully appraised of the research project
- consent to be observed and interviewed.

**RNs who**

- work in a RACF
- are involved in taking care of residents who are enrolled in the ACP program
- speak English
- consent to be observed and interviewed
- have a minimum of two years full-time or equivalent of work experience in caring of elderly residents. It is assumed that this period is long enough for staff to have an understanding of end-of-life care issues for residents.

**3.9.4.2 Recruitment of the CNC**

The researcher met the ACP program manager, who was the CNC, at a national conference in November, 2004. A brief description of the research project was given to the CNC and she expressed her willingness to participate in the research project. She offered the researcher help, if required, in developing a comprehensive research proposal. The CNC invited the researcher to join her for two days in February, 2005. This preliminary work was crucial for the researcher, in order to develop the research proposal in detail.

In preparation for the study the researcher undertook some preliminary analysis of existing services for ACP. The preliminary work to develop the research proposal is depicted in

Appendix 8. Identification of the existence of the only CNC focused on ACP enabled preparatory exploration of potential sites and personnel. The CNC provided an overview of her scope of practice and sphere of activities. The latter included minimal details of interactions between the regional AHS in which she was employed and RACFs in the same region. The researcher has no prior work experience with the CNC, expertise with ACPs or any prior knowledge of any of the proposed RACFs. However, the researcher does have experience in working in other RACFs, which enhanced her understanding of the phenomenon.

The CNC was given the research proposal to review in September, 2005, which elaborated the data-collection process and what was required of her if she decided to participate in the study. She was also informed that the research proposal was approved by the Human Ethics Research Committee (HERC) at the University of Newcastle in September, 2005. Given that she was the only person in NSW who had implemented the ACP program in RACFs, her concerns about confidentiality and privacy were discussed and addressed to the fullest extent. The CNC requested no further explanation and was satisfied with the process of data collection and the extent of her involvement in the research project. The CNC had consented to be observed and interviewed in October, 2005.

The researcher has selected the only expert in ACP who was not only willing to participate in the study but who also held a key position, aligning the acute care sector and RACFs, and has special knowledge of the phenomenon under study (Morse & Field, 1995).

#### 3.9.4.3 Recruitment of residents

Residents were recruited by the CNC from the list of older people who registered for the ACP program. When the CNC had a referral for ACP, and if the older person met the sample criteria, she asked if the person was interested in the research project and would like to know more about the project. The CNC recruited the potential resident participants not only from the three participating RACFs but also other RACFs that she visited in order to maximise the number of residents who met the sample criteria. The researcher was not told how many and who met the criteria, thus preventing the researcher from coercion of potential participants for

the study. With the permission from the older person, the researcher visited him or her in the facility. Information about the research project, in particular about the interview, was given and responses made according to what they wanted to know. Rather than sending the potential participants a written letter by post, they were informed of the research project face-to-face if they were interested in knowing more about the project. This approach was suggested by the researcher, as she realised that the elderly residents might prefer a personal verbal explanation about the research project to three pages of a written information letter that were part of the requirements from the Ethics Committee. This was also supported by the CNC and the DONs who reviewed the information letter and who confirmed that initial verbal conversation would minimise any discomfort and misunderstanding that the formal information letter might cause and maximise their willingness to participate in the study. The potential resident participants were asked in the initial face-to-face contact with the researcher if they would want further information about the research project in written form.

The researcher then prepared and distributed the envelopes on which she had written the potential participants' names enclosing an information letter (see Appendix 9), consent form (see Appendix 10), and a postage-paid return envelope. The consent form provided the opportunity for study participants to choose to be observed during ACP processes or interviewed or both. They were informed of where the envelope return box was in the facility but they all returned the consent forms to the researcher while she was around the facility doing observations. Most of the residents in high-care facilities did not meet the sample criteria, due to cognitive impairment. Three residents in high-care and two in low-care facilities were contacted by the researcher and consented to the interview. One resident in high care died two days before the interview appointment, and another resident with Motor Neuron Disease (MND) in high care withdrew from the study, as his condition deteriorated and he was unable to talk. Finally, one resident in high care and two residents in low care were interviewed by the researcher. This number of participants provided sufficient data to achieve saturation and enabled a full description of the phenomenon of ACP.

#### 3.9.4.4 Recruitment of family members

Family members were recruited by the CNC and the DONs in each facility. When the CNC

had contact with a family member for ACP, she asked if the family member was interested in the research project. The DONs in each facility identified the family members who met the sample criteria in the facility and who wanted to know more about the research project. The researcher was informed of those family members and with their permission, she approached the family members one by one, in private, during their visit in the facility. At that time, information about the research project, in particular about the interview, was given to the extent that they wanted to know it. The potential family member participants were asked in the initial face-to-face contact with the researcher if they wanted further information about the research project in written form. Some family members directly expressed their interest in research and requested further written information while the researcher was around the facility doing observation. The researcher's presence in the facility generated interest from the family members who were regularly visiting. Some of them expressed their wishes to participate in the study but the researcher politely had to decline their consent, as they did not meet the sample criteria.

The researcher then prepared the envelopes on which she had written the potential participants' names enclosing an information letter (see Appendix 9), consent form (see Appendix 10), and postage-paid return envelope addressed to the facility with the researcher's name on it. The envelopes were posted by an administrative staff member in each facility so the potential participants' privacy was maintained and the possibility of coercion to participate in the study by the researcher was minimised. Some family members returned their consent to the researcher directly while she was around the facility and some posted their consent to the facility, marked to the researcher and the administrative staff passed the envelopes returned to the researcher. The researcher re-contacted only those family members who gave consent for an interview, to negotiate the time and venue. The potential participants were given three weeks to return the consent forms. The researcher planned to distribute a reminder letter (see Appendix 11) one week prior to the due date for the consent form collection but this was not necessary as all the consent forms distributed were returned to the researcher before the due date. The CNC and the DONs were not given the names of the participants and this ensured that the participants and non-participants were not treated differently in the facility. Finally, eleven family members were interviewed by the researcher. This number has generated saturation of the data for adequate descriptions of the phenomenon of ACP.

#### 3.9.4.5 Recruitment of the RNs

The RNs were recruited by the DONs in each facility. The DONs were asked to estimate the number of RNs who met the sample criteria for the study. The researcher prepared the envelopes and the DON distributed the envelopes on which she had written the potential participants' names enclosing an information letter (see Appendix 12), consent form (see Appendix 10), and envelope. The researcher placed a bright yellow distinctive envelope return box in the staff common room in each facility. The RNs were informed of where the envelope return box was in the facility. The potential RN participants were given three weeks to return consent forms and they were reminded by the reminder letter (see Appendix 11), which was placed in the RNs' communication book one week prior to the due date for the consent-form collection day.

The researcher was not told how many and who met the criteria, thus preventing the researcher from applying coercion to participate in the study. The DONs were not given the names of the RNs who decided to participate and this ensured that the participants and non-participants were not treated differently in the facility.

The researcher was available in the facility in case the potential participants had any concerns or questions. The researcher provided further information to the RNs, upon their request, about the research project and what was required of them if they decided to participate in the study. Finally, 13 RNs, including the CNC, were interviewed by the researcher. This number has achieved saturation of the data set which facilitated description of the phenomenon of ACP in RACFs.

Morse and Field (1995) discussed qualitative research and noted that sample size could be judged as adequate when no new information was being generated and participants were echoing each other. The final sample size for this study that was necessary to generate adequate descriptions of the phenomenon were three residents, 11 family members, and 13 RNs including the CNC. The demographic characteristics of the participants are depicted in Table 3 – 1, 3 – 2, and 3 – 3.

Table 3 – 1. Demographic Characteristics of Residents

Code	Age	Sex	Medical Diagnosis	Marital Status	Frequency of contact with immediate family
Resident 1	68	Female	Chronic Pancreatitis, Oesophagitis	Never married	None
Resident 2	79	Female	Tumor inflammable Pseudo, Gall Stone	Married	Daily
Resident 3	94	Male	Heart failure, NIDDM, Prostate cancer	Never married	2 – 3 times a week

Table 3 – 2. Demographic Characteristics of Family members

Code	Age	Sex	Relationship to the resident	Marital Status	Frequency of contact with the resident
FM 1	85	Male	Husband	Married	Daily
FM 2	62	Female	Daughter	Married	Weekly
FM 3	59	Male	Son	Married	Fortnightly
FM 4	Not revealed	Female	Daughter	Single	Daily
FM 5	52	Female	Niece	Single	3/ week
FM 6	90	Male	Brother	Widower	3/ week
FM 7	61	Male	Son	Married	Weekly
FM 8	52	Female	Friend	Divorced	8 – 10/ week
FM 9	26	Male	Brother	Single	Fortnightly
FM 10	60	Female	Daughter	Married	Daily
FM 11	61	Female	Daughter	Married	3 – 4 / week

Table 3 – 3. Demographic Characteristics of Registered Nurses

Code	Age	Sex	The work hours in the NH	Years of experience in this NH	Years of experience in Aged Care
RN 1	57	Female	38/ week	3 years	32 years
RN 2	48	Female	38/ week	7 years	8 years
RN 3	62	Female	16/ week	6 years	6 years
RN 4	53	Female	38/ week	11 years	11 years
RN 5	60	Female	31/ week	29 years	29 years
RN 6	56	Female	38/ week	18 years	25 years
RN 7	44	Female	20/ week	3 years	5 years
RN 8	50	Female	38/ week	5 years	20 years
RN 9	54	Female	20/ week	2 years	25 years
RN 10	49	Female	38/ week	16 years	27 years
RN 11	50	Female	38/ week	4 years	22 years
RN 12	39	Female	38/ week	3 years	9 years
RN 13 (CNC)	48	Female	38/ week	5 years	24 years

#### 3.9.4.6 Interview foci

Following the acquisition of formal consent, the researcher conducted semi-structured and face-to-face interviews in the RACF with the residents, family members, and RNs. The researcher conducted at least one interview session with each participant. The researcher conducted the interviews, which were tape-recorded and transcribed verbatim. Consenting participants were all invited to participate in interviews conducted throughout the three to six months' observation period. Interviews were undertaken individually. Only one significant family member from each family was interviewed. Multiple interview sessions with each study participant were also offered by request and one RN requested two interview sessions with the researcher. The interview questions have been developed by the researcher and were based on insights gathered empirically from her participant observations, informal conversations with study participants and contemporary literature.

The residents who enrolled themselves in ACP program and gave consent to participate in the research were interviewed. They were asked what they understood about the program, why they decided to document ACDs, how they felt about it, and if they had any concerns with regard to documenting ACDs. They were also provided with opportunities to talk about their experiences with the ACP program.

The family members of residents were invited to be interviewed. They had an opportunity to talk about what they understood about the program, if applicable, what they believed the role of the person responsible is, how they felt about it, and if they had any concerns. The family members had an opportunity to discuss what they experienced as ACD documents were completed. The family members of the residents who passed away during the data-collection period would have been able to describe which aspects of the ACD documents were able to be followed, what factors either promoted or interfered with adherence to the residents' wishes, and what they would like to put in words about the death of the residents. However, none of the resident participants passed away during the data-collection period. Therefore, the researcher was not able to explore the above aspect.

The RN participants were invited to express their perceptions about and experiences with ACP



program and ACDs in the RACF context, particularly attitudes, beliefs, comfort, and confidence dealing with these issues. They also had an opportunity to talk about what they understood about ACP and ACDs, if applicable, what they believed the role of RNs was, how they felt about it, and if they had any concerns. Some RNs were able to describe which aspects of the ACD documents were able to be followed, what factors either promoted or interfered with adherence to the residents' wishes, and what they would like to put in words about the death of the residents. Interview schedules with suggested prompts for the researcher are attached in Appendices 13 and 14.

Follow-up informal conversations between the RNs led to an unexpected networking effect. The RNs who completed interviews informed their colleagues what it was like to be interviewed and reduced some of the fear that the potential participants might have had in their minds. This resulted in increasing the willingness to participate in interviews within the facility. Also, at the time of some interviews, other RNs who were on duty negotiated interview times. All participants who had given the researcher consent to interview were interviewed. One RN participant went on annual leave for six weeks after she provided the consent and she was interviewed after she came back from her leave.

Each case therefore involved a triple perspective (resident, family member, and RN). Each interviewee was invited to view the transcripts of her/his interviews after the interviews were transcribed and one RN participant took the opportunity to review the transcripts and made minor changes to elaborate on her views. Transcribed interview data were subjected to content analysis in order to answer questions based on the propositions emerging from the literature.

### **3.10 Duty of care to participants and others**

The researcher has taken into account the fact that the value of the best research is not likely to outweigh injury to a person exposed (Stake, 1994). The researcher made every attempt to ensure that the comfort and well-being of the participants were not compromised in any way for the sake of data collection. Being observed by a stranger and discussion about end-of-life care issues can be stressful. In the event that participants became distressed during data collection, the researcher offered to stop the process and notified the DON responsible for

the care of residents, family members and nursing staff. For example, an RN who consented to be observed was distressed because of an event that had occurred in the facility so the researcher withdrew herself from the setting temporarily and it was appreciated by the RN as a sensible action. Another example is that a female family member burst into tears when she talked about her mother's life and how precious her mother was to her. However, she wanted to keep talking and then indicated appreciation of the researcher for the opportunity to get the things 'off her chest'.

The researcher made sure that there was no imminent health problem during the interview with the participants, especially the residents. There was no occasion on which the researcher had to refer the participants to the staff to seek medical attention. The researcher tried to provide comfort at all times. In case there was an urgent medical issue, the researcher provided appropriate care as an RN as necessary, as well as involving nursing staff from the facility. For example, whilst the researcher was observing in the small dining area in a facility, a male resident had a fall and was bleeding from his forehead. An AIN who was nearby was sent to get more help while the researcher provided him with appropriate care. The researcher offered help to an RN on duty in sending him to the hospital for x-ray and stitches. The researcher was appreciated for her quick and professional care by the facility and the family members of the male resident.

### **3.11 Ethical considerations**

The researcher has undertaken a number of strategies to ensure all the ethical principles were considered and adhered to while conducting the research project. Ethics approval was obtained from the University of Newcastle in September, 2005 and the regional AHS in February, 2006. Other strategies undertaken by the researcher to ensure informed consent, voluntary participation, and protection of privacy, confidentiality and anonymity are as follows.

#### **3.11.1 Informed consent**

- The potential participants were provided with a sufficient amount of information in the information letter and in a face-to-face discussion with the researcher on request.

- An announcement note (see Appendix 4) about the research was attached on the residents' and staff's noticeboard to advise them of the research project in progress.
- The potential participants were informed in the information letter about the aims of the study, expectations of participants, their rights to full information, freedom from coercion, confidentiality of information gained from them, anonymity within any report, the right to withdraw from the research at any time without explanation. They were then provided with time to consider whether they wanted to participate or not.
- The potential participants were also informed of the benefits and risks of participation in the study. The benefit to the residents and family members centres on the provision of care consistent with their wishes. They also had an opportunity to express themselves about the program, concerns, feeling, worries, and thoughts during the interview. There was no anticipated risk or disadvantage from participating in the study, as all participants received usual care. There was a risk that in the course of interviews, participants might become distressed when sharing their experiences of ACP. They were informed that in such instances, the researcher would offer to terminate the interview and offer counselling as needed.

### 3.11.2 Voluntary participation

- The researcher only approached eligible participants after initial contact with them by the DON of each RACF in order to seek their interest in hearing more about the study. Where the eligible person agreed to hear more about the study, the researcher provided detailed information and explanation. Information letters with an invitation to participate in the study and consent form for the observation and interview were only given by a third person (DON, administrative staff, CNC) to residents, their family members and associated RNs who met the sample criteria. They were then invited to consider their participation and submit a consent form at their convenience and as noted in the information letter. This ensured the potential participants felt free

to make a decision to participate or not to participate without being disadvantaged in any way. No inducements or monetary rewards were provided.

- Only those who consented to participate in the study were asked to return the consent form to a box located in the RACF or through the return postage-paid envelope provided. This approach has minimised the discomfort and pressure that the potential participants might have experienced if they had to return the forms to the researcher directly, regardless of their willingness to participate.
- The DON was asked to estimate the number of potential participants who met the sample criteria for the study. The researcher prepared envelopes enclosing an information letter and consent form for the interview. The DON personally distributed the envelopes on which she had written the potential participants' names. Therefore, the researcher was not told of who met the criteria, thus preventing the researcher from applying coercion to participate in the study. This allowed the researcher to remain at arms' length from participant recruitment. The DONs were not told the names of the participants. This ensured that the participants were not treated differently by the DON.
- The researcher checked at the commencement of the interviews that all parties were happy to proceed.
- The researcher also sought additional verbal consent from the participants (including all relatives present) prior to any periods of data collection and before any types of data collection began.

### 3.11.3 Protection of participants' privacy, confidentiality, and anonymity

- The DONs in each facility and the CNC were not able to identify who had or had not returned the consent form to the researcher, so the potential participants were protected from being disadvantaged in any way.

- Participants' names were not used in transcriptions of interviews or in the recording of field notes. The researcher was well aware of the need to ensure the participants' privacy be strictly protected. Personal information that was not necessary for the recruitment process or relevant to the scope of the study was not sought.
- All participants were assigned a coded identification number which was used on all transcriptions. Participants were not identified by name in presentations, publications or within the thesis. All data stored in the researcher's computer was password-protected. All data collected during the study were locked in a file cabinet located at the office of the researcher at the University of Newcastle. Only the researcher and the supervisors had access to data.
- The person who transcribed the interview data was advised about confidentiality, anonymity and privacy, and asked to sign the form (see Appendix 15).

No ethical issues specific to the study and to the researcher's manner have been identified or complained about by any person at the completion of the study.

### **3.12 Data analysis**

According to Denzin and Lincoln (2005), a montage is the whole picture of a phenomenon created by several different images that are juxtaposed or superimposed on one another. Multiple voices, various perspectives, and different angles of vision are represented in a montage. The researcher stitches, edits and puts slices of each image together, and understandings created by each image and the images, as a set, blend, contrast and form a new creation. Then those who view the montage are invited to perceive and construct interpretations that are based on the new creation. The montage reflects the researcher's attempt to secure an in-depth understanding of the phenomenon in a way that what is formed is what had been separated, and what is created is what had not presumably existed.

The current research project was undertaken to show a montage that was the phenomenon of ACP. The researcher collected stories and images from residents, families and nurses in relation to ACP in RACFs. The images focused on each research question appeared as one whole montage of ACP. Various techniques were used to capture multiple images of the phenomenon. For example, the questions asked to each group of participants were similar but unique to their own nature in ACP to reflect various perspectives. The four data-collection methods (participant observation, field notes, semi-structured interview, and documentation analysis) were mutually assistive in collecting different images from different angles. In particular, the time spent (day, evening, and night shifts on weekdays and weekends) in the natural setting provided the researcher with an opportunity to collect rich and affirmative images of the phenomenon.

Once the images and stories were collected, the researcher adopted a Critical Incident Technique (CIT) and used thematic content analysis. CIT is defined by Flanagan (1954, p. 327, 335) as

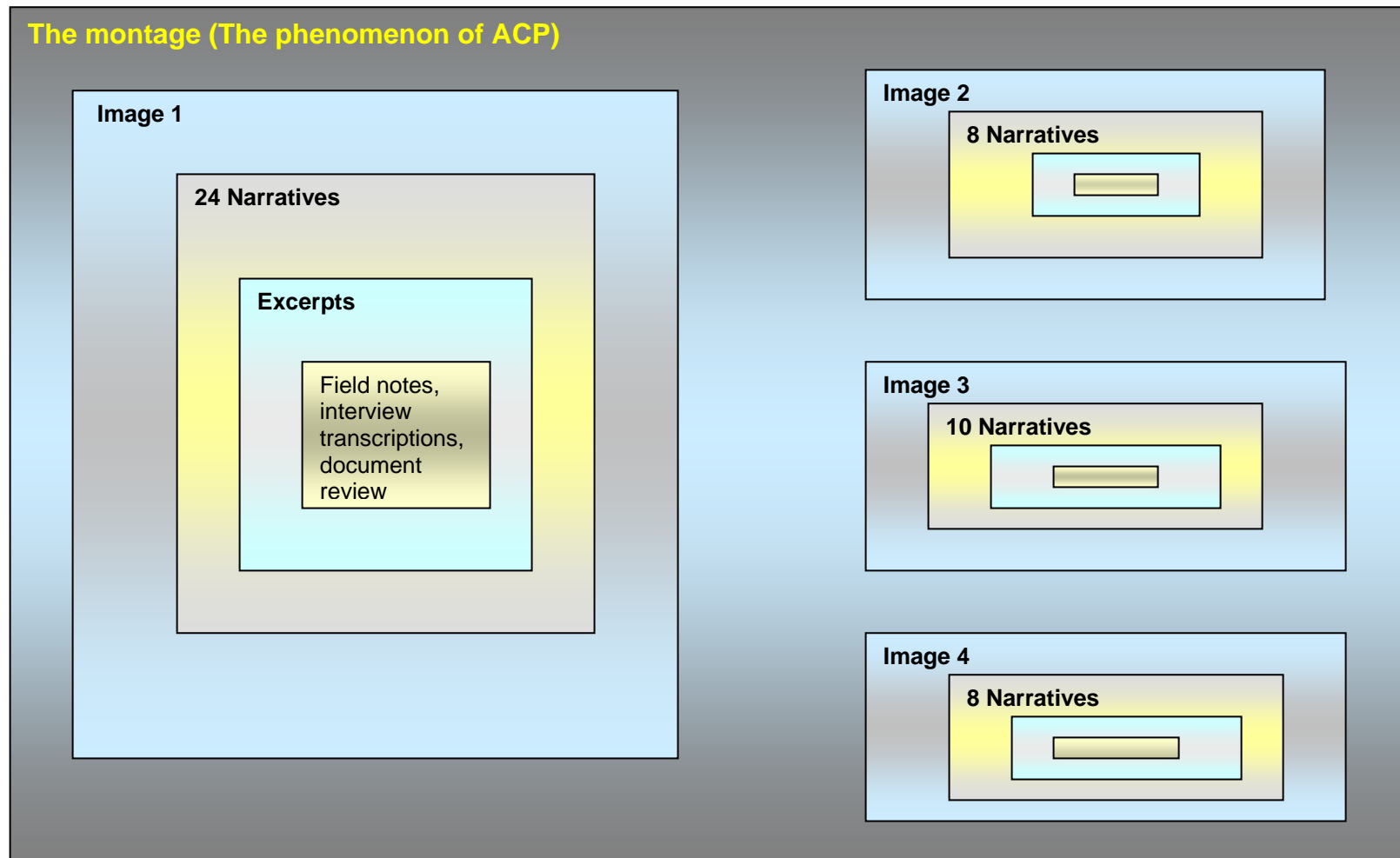
a procedure for gathering certain important facts concerning behavior in defined situations and an incident is deemed critical where the purpose or intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effects.

The CIT was originally developed in the 1950s by the aviation psychologist Flanagan, however, its use in various disciplines over the ensuing decades positions it as a valuable methodology to collect 'direct observations of human behaviour in such a way as to facilitate their potential usefulness in solving practical problems (Beech & Norman, 1995; Flanagan, 1954). The CIT in the nursing context is recognised as a helpful, versatile and highly flexible qualitative research method to examine nursing issues and reveals the subtleties and complexities in nurses' experiences of practising nursing in diverse contexts (Keatinge, 2002). Using CIT also allows nurses to understand the dimensions of their roles in the clinical setting and their interactions with patients and other clinicians, and provides insight into nursing issues in data collection, interpretation, and analysis (Byrne, 2001; Kemppainen, 2000). The data collected from interviews and field notes were gathered and highlighted where they concerned behaviours, feelings, attitudes, opinions, comments and perceptions in relation to each research question for further extensive thematic content analysis.

Analysis of data collected from a case study also followed Yin's (2003b) strategy, which recommends thematic content analysis to analyse the data, because the data obtained from the transcripts were narratives, stories and experiences of the participants. This method involved reading, browsing, reflection, coding, validation of codes and searching for emerging patterns in the data. This facilitated the generation of categories relevant to research questions through this process. Axial coding is a way to relate subcategories to categories, then to discover categories in terms of a paradigm model, which was used to identify relationships and connections between categories (Strauss & Corbin, 1990). Axial coding suggested by Strauss and Corbin (1990), and which is unique in its way of making comparisons and asking questions of the data in relation to the research questions, was applied in order to address the whole picture of the case study (Yin, 2003b). The software program called 'NVivo 7' helped the researcher to code and categorise large amounts of narrative text which were collected from open-ended interviews. An audit trail of the data analysis is contained in Appendices 16 and 17.

The researcher gathered, edited, cut, stitched, highlighted, excerpted, synthesised, prioritised and discarded information in order to lay out all the images in relation to the phenomenon of ACP. The raw data to which the CIT and thematic content analysis were applied generated four images corresponding to the four research questions consisting of 50 narratives that completed the montage. The diagram of the analysis process is depicted in Figure 3 – 2. The four major images created by these narratives in relation to each research question comprised the entire montage of the phenomenon of ACP in RACFs. The researcher provided the readers with narratives created in four images in relation to each research question, outlined in Table 3 – 4.

Figure 3 – 2. The diagram of the analysis process





**Table 3 – 4. Research Questions with Narratives**

<b>Research Questions</b>	<b>Narratives</b>	<b>Page No</b>
1. How and why are ACP and the use of ACDs implemented by the CNC in RACFs?	1. ACP was included in our organisational policy and manual and we support the nursing staff to do it.	108
	2. There is no legislation but there are Guidelines.	109
	3. We want to know what they want, as they have the right to choose.	110
	4. They have to suffer to have ACP.	111
	5. She has been like a white light.	1113
	6. Families of incapable residents can do a POT.	115
	7. Documentation was embedded in the process for incapable residents.	117
	8. Documentation was only a tool to help me find out who the person has been.	119
	9. The questions in ACDs and POT are comprehensive and extensive.	122
	10. All will be discussed in the case conference.	125
	11. Nurses know how to help people in case conference.	126
	12. Discussion is about giving people a choice and counselling them through.	127
	13. Discussion should promote conversation and explore all the possibilities.	129
	14. The in-service education did a lot to us.	131
	15. They would have had to go to hospital without multidisciplinary team.	132
	16. We need to do better in communication.	135
	17. We don't know much about the legal side of ACP but we are not worried.	138
	18. We waited for deterioration.	141
	19. Then it was too late.	142
	20. We don't know the best time to do it. It may depend on the person.	144
	21. ACP/ACDs/POT as taboo subjects.	147
	22. Lack of commitment by managers, RNs and GPs.	148
	23. High turnover and lack of consistency in attendance.	149
	24. The terms are not familiar and abstract thinking is hard.	151
2. What are the outcomes of ACP for residents, family members, and RNs?	25. 'No hospitalisation' and 'no CPR' because it doesn't do good, there is no benefit, no dignity.	155
	26. Palliative care and beyond.	156
	27. 'No tube feeding'.	158

	28. It gave us clear direction of what to do.	160
	29. What we do is an absolutely person-centred care.	162
	30. It is a dignified way to go.	165
	31. I started thinking about end-of-life care and talked to my family.	166
	32. We want to discuss our choices.	168
3. How do residents, family members, and RNs perceive their experience with ACP and ACDs in RACFs?	33. 'Essence of Being' was enhanced through ACP.	179
	34. Transcendence: I had a good life, use the resources better.	183
	35. Autonomy in social context; my right, my responsibility but we all need back-ups.	185
	36. I surrender. Why prolong? No point!	188
	37. The involvement of hospital care teams in ACP was the utmost endeavour & the ultimate hope was that I can revoke it.	190
	38. We don't understand the readings, so talk to us.	193
	39. I am worried that I won't be left alone.	195
	40. Culture of 'do everything'.	195
	41. Culture of 'don't go there'.	196
	42. Lack of family involvement in care.	197
4. How is the scope of practice perceived by the CNC and the RNs in ACP in RACFs?	43. ACP is a process that promotes health and well-being.	210
	44. It is hard to think about what I will be and what I will do when I am not myself.	211
	45. Initially, not many residents were competent to document ACDs and not many families wanted to know more about ACP.	214
	46. Education was one of the most important functions in ACP process.	217
	47. Everyone is passing the buck with no understanding of each other's roles.	219
	48. The RNs' roles in ACP were minimal and limited.	223
	49. Routinising ACP and having one designated person is the way to go.	228
	50. We are not research-active yet.	231

## Conclusion

In this chapter, the researcher explored the definitions of case study as a research methodology. Case studies have been used in many disciplines including psychology, sociology, history, anthropology, political science, and economics. Case-study research provides an avenue to understanding the implications of changes in nursing practice given its capacity to allow for the study of human phenomena in the real world as it happens. The researcher used data sources and method triangulation focusing on ‘construct validity’ and ‘external validity’. The rationale for the choice of case-study research was justified given that the phenomenon of ACP in RACFs had not been rigorously studied and the focus was on a contemporary phenomenon within real-life context.

Data were collected in three RACFs on the basis of accessibility, timing, their involvement in ACP Program, and their willingness to participate in the study. Data collection in the study included document analysis, semi-structured interviews and ongoing participant observation. Data were analysed using CIT and thematic content analysis in order to capture the montage of the whole picture of the phenomenon. The researcher projected four different images that arose from multiple voices, various perspectives, and different angles of vision in an attempt to ensure an in-depth understanding of the phenomenon of ACP in RACFs.

The readers are now invited to visualise and interpret the new creation of the phenomena of ACPs and ACDs, presented in Chapters Four and Five.

## Chapter 4

### The Findings: Part One

#### Introduction

The findings of the study are presented in Chapters Four and Five. Given that the ACP processes implemented and the experiences of people involved in those processes were complicated and sensitive, the researcher plans to unfold the findings in a systematic way in order to enhance the reader's appreciation of the complex phenomena underpinning ACPs.

In Chapter Four, the researcher presents how and why the ACP and the use of ACDs were implemented by the expert nurse in RACFs, and what the outcomes of ACP were for residents, family members, and RNs. Then the researcher describes how the residents, family members, and the RNs perceived their experience with ACP and ACDs in Chapter Five. The scope of nursing practice in ACP is presented also in Chapter Five. Table 4 – 1 provides an overview of the alignment of Figures and Tables to research questions.

**Table 4 – 1. Research Questions with Figures and Tables**

<b>Research questions</b>	<b>Figures &amp; Tables</b>
1. How and why are ACP and the use of ACDs implemented by the CNC in RACFs?	<ul style="list-style-type: none"> <li>• Figure 4 – 3. Conceptual Framework for Implementation of ACP (see Input &amp; Throughput)</li> </ul>
2. What are the outcomes of ACP for residents, family members, and RNs?	<ul style="list-style-type: none"> <li>• Figure 4 – 3. Conceptual Framework for Implementation of ACP (see Output)</li> </ul>
3. How do residents, family members, and RNs perceive their experience with ACP and ACDs in RACFs?	<ul style="list-style-type: none"> <li>• Figure 5 – 1. Conceptual framework for experience of residents, family members, and RNs with ACP</li> <li>• Table 5 – 1. Factors influencing the transition</li> </ul>
4. How is the scope of practice perceived by the CNC and the RNs in ACP in RACFs?	<ul style="list-style-type: none"> <li>• Figure 5 – 2. Nursing Brokerage Model A in ACP</li> <li>• Figure 5 – 3. Nursing Brokerage Model B in ACP</li> <li>• Figure 5 – 4. Nursing Roles and Functions Model in ACP</li> </ul>

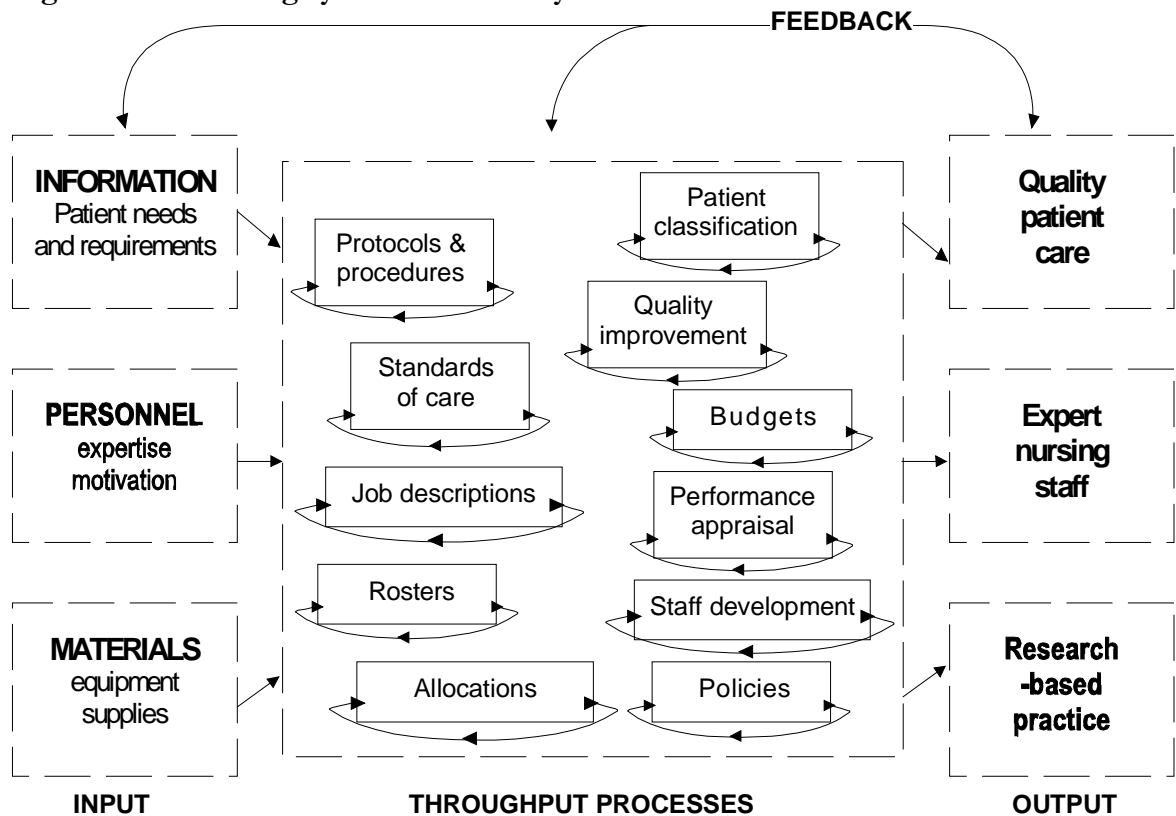
### **Conceptual framework for research questions 1 and 2**

In order to constructively analyse and present the data in relation to the implementation of the ACP Program and the use of ACDs in RACFs, it was necessary to adopt a conceptual framework that would help to guide the analysis of data and explain the parameters and elements of the ACP.

The conceptual framework utilised to direct the study was modified from the work of Axford (1995) following the identification of the main themes within the process of ACP implementation and the use of ACDs in RACFs. Axford developed a nursing system framework (see Figure 4 – 1) based upon the work of Von Bertalanffy (1968). The general system theory was introduced by Ludwig Von Bertalanffy (1968) as a mode to establish general principles for systems, for organised entities irrespective of their physical, biological or sociological nature and it has revealed basic principles by collating the common properties of a variety of systems. Von Bertalanffy (1975, p. 11) emphasised that general system theory is multidisciplinary and has been adopted by many disciplines when there was a strong requirement to deal with complexities, with ‘wholes’ or ‘systems’, in all fields of knowledge.

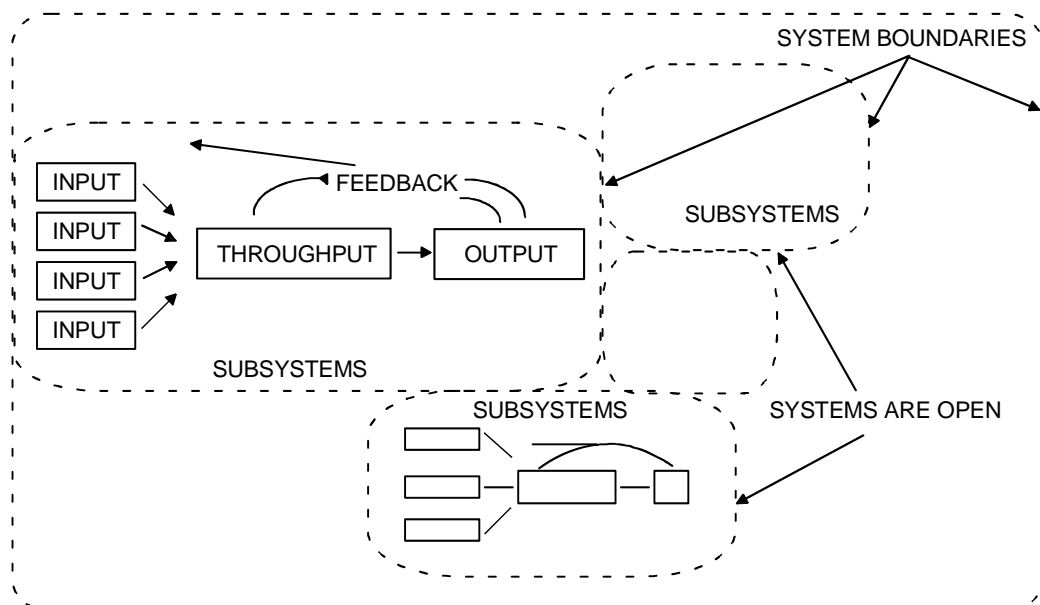
The classic elements of system theory are depicted in Figure 4 – 2 (Axford, 1995) and the core concepts in systems theory are presented as follows. Systems are referred to as sets of elements standing in interrelation among themselves and with the environment (Von Bertalanffy, 1975, p. 159). Larger systems are made up of smaller, interconnected sub-systems. Systems may be said to be open or closed depending on whether or not they communicate with a larger ‘outside world’ or system. The points of connection between sub-systems are called boundaries (Axford, 1995). Closed systems are those which are considered to be isolated from their environment, such as thermodynamics. There are also open systems which are self-maintained in a continuous way by accommodating in-and-out flows. By their nature they are similar to a living organism or a society (Von Bertalanffy, 1968). According to Von Bertalanffy (1975), a system maintains itself in a state of highest organisation as a result of a continuous process of build-up and break-down, therefore, it is not static but dynamic and active as the result of a stream of events for which we must find laws. This state of improbability and growth is captured in input, throughput, output, and feedback in each system (or sub-system).

Figure 4 – 1. Nursing systems and sub-systems



Axford, R. (1995). The context of nursing care delivery. In A. Nolan. & L. Hazelton. (Eds.), *The practising nurse* (pp. 95 – 131). Sydney: W.B. Saunders.

Figure 4 – 2. Classic system elements



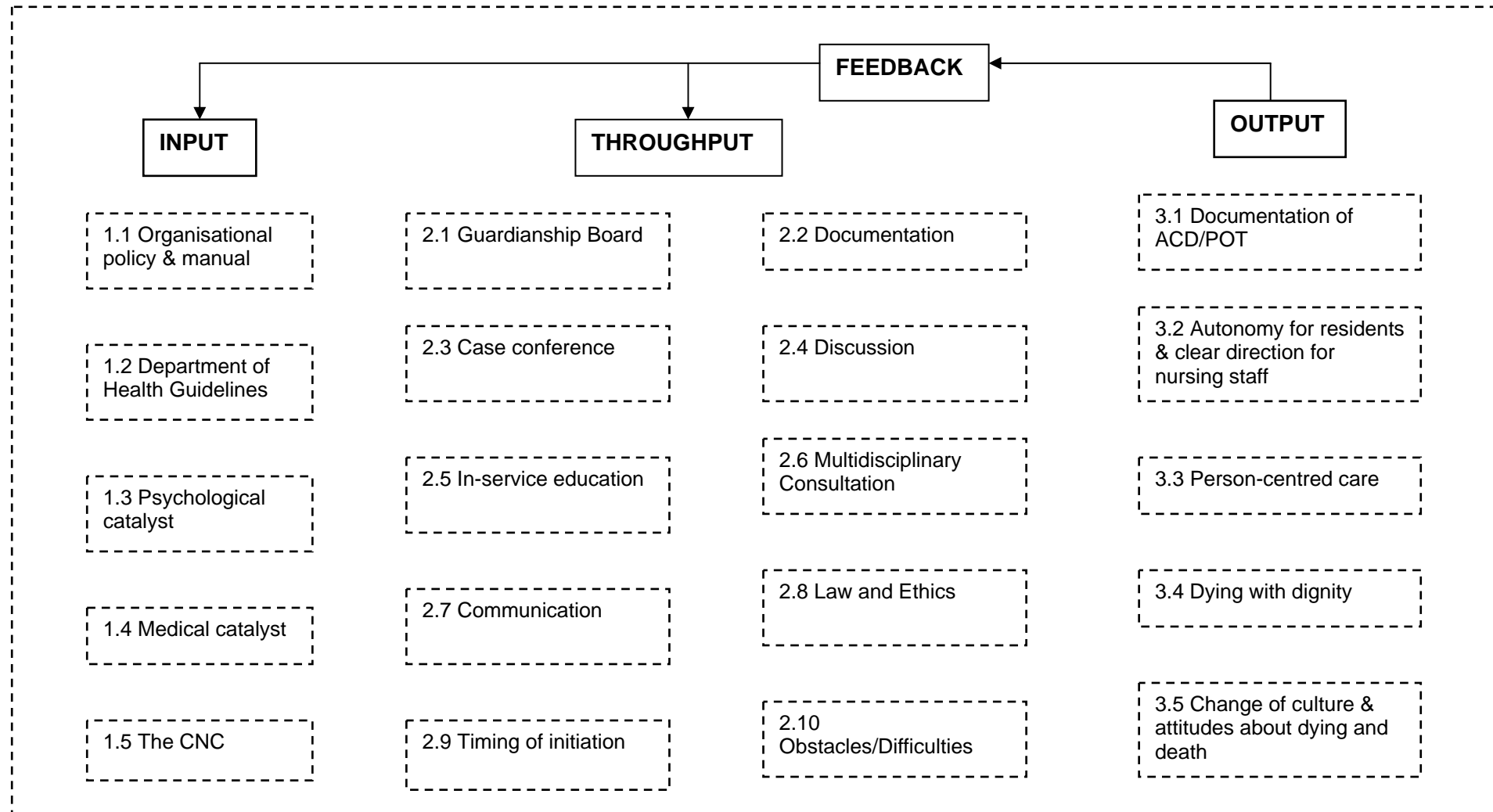
Axford, R. (1995). The context of nursing care delivery. In A. Nolan. & L. Hazelton. (Eds.), *The practising nurse* (pp. 95 – 131). Sydney: W.B. Saunders.

The choice of conceptual framework to direct the study was influenced by a need to find a mechanism to accommodate the recognised complexities of and issues of the ACP program in the implementation process. The framework was also seen as an appropriate way of organising the evidence from actual observations and interviews on the outcomes of ACPs and ACDs documented. It enabled the researcher to examine the forms, policies, and philosophies that the process might take, the information needed to function, and how the expert nurse interacted with people involved in providing care of the older persons. It provided the opportunity to systematically identify components and factors involved in the ACP process and in attaining desired outcomes. The conceptual framework that allowed the researcher to fully address the answers to the research questions 1 and 2 is depicted in Figure 4 – 3.

The conceptual framework (Figure 4 – 3) consists of the four main elements: input, throughput, output, and feedback and twenty sub-elements. The first element of the ACP process focuses on input and incorporates the following sub-elements that are necessary to implement ACP and to attain desired outcomes:

- Organisational policy and manual: any information or documentation written with regard to ACP and ACDs in order to give the staff direction in providing end-of-life care within each organisation.
- NSW Department of Health Guidelines (2004): the Department of Health in NSW endorses the concept of ACP and developed guidelines. ‘Using advance care directives’ was published in 2004 in order to provide to health professionals on the best practice use of advance care directives within an advance care planning process. ‘Interim guidelines on dying with dignity’ (Chiarella, 1994) was replaced by ‘Guidelines for end-of-life care and decision-making’.
- Psychological catalyst: the psychological grounds that motivate conversation about ACPs.
- Medical catalyst: medical conditions or acute health breakdown episodes that contribute to initiation of the ACP process.
- The expert nurse: the broker with expert knowledge and experience in ACP.

Figure 4 – 3 Conceptual Framework for Implementation of Advance Care Planning



Modified from General System Theory by Von Bertalanffy (1975)



The second element of the ACP process is the throughput component, which refers to the ten sub-elements that all the participants being involved in ACP process have to work with or through to bring about outcomes. The throughput process consists of the following sub-elements:

- Guardianship Board: promotes fairness and seeks to safeguard both residents and health-care professionals in the ACP process. It sets the hierarchy of Person Responsible (PR) in the decision-making process. It liaises with the Office of Public Guardian (OPG) as necessary.
- Documentation: refers to the paperwork that all the participants involved in the ACP process need to complete and that will facilitate the ACP process. It includes the Mini Mental Status Examination (MMSE), Geriatric Depression Scale (GDS), Value Clarification Worksheet, ACP Nursing Home Project Assessment Form, Admission package in each RACF, ACD form, Plan of Treatment (POT) form, etc.
- Case conference: refers to the meeting at which the conversation about end-of-life treatment options occurs between resident, family member, GP, the CNC, RN, AIN, and other health professionals.
- Discussion: refers to the conversation that occurs with regard to ACP and ACDs between resident, family member, GP, the CNC, RN, AIN, and other health professionals.
- In-service education: refers to the information session delivered by the CNC about ACP and ACDs to resident, family member, RNs, GP, A & E staff, and other health professionals.
- Multidisciplinary consultation: refers to the conjoint effort by health-care professionals involved in the ACP process. It includes Post Acute Care Service (PACS), Palliative Care team, Accident & Emergency (A & E) Department, geriatrician, GP, psycho-geriatrician, neuro-psychologist, and after-hours doctors.
- Communication: refers to the way to deliver outcomes of discussions and decisions made in the ACP to the staff in each RACF, hospital, and GP. It includes verbal and written communication methods.
- Law and Ethics: refers to legal and ethical boundaries that all the participants need to work through/for/within in order to produce legally and ethically sound decisions.

- Timing of initiation: refers to the opportunity or circumstance in which the initiation of conversation about end-of-life care preferences occurs.
- Obstacles/difficulties: refers to hindering factors in ACP that were experienced by residents, family members, and the RNs.

The third element of the system is output, which refers to the achievements that these elements produce in nursing-care delivery through feedback and as a result of well-balanced inputs and throughput processes. The products that these sub-elements bring into end-of-life nursing practice are as follows.

- Documentation of ACDs/POT
- Autonomy for residents and clear directions for nursing staff
- Person-centred care (PCC)
- Dying with dignity
- Change of culture and attitudes about dying and death.

The fourth element, feedback, indicates ways in which the functioning of the output elements are monitored and evaluative information is fed back to the input and throughput elements. This makes the system self-regulating and directs ongoing action. However, there is no evidence that indicates for example, that resource A flows through process B and then produces output C. This framework should be considered as a whole and the desired outcomes are only the symphony of inputs and throughputs in a dynamic and active motion. The conceptual framework identified revealed that the ACP Program was initiated with a few sub-elements in the early stage. For example, the resources available in the ACP Program in the early stages of implementation processes were the expert nurse and other psychological catalyst. Department of Health Guidelines were not available until 2004 and the organisational policy and manual to support the staff in ACP took some time to be developed within each organisation. It was suggested that the framework was complete in its own context at the time of data collection, as the result of constant feedback and ongoing action between the elements and sub-elements of the implementation process.

The three sections in this chapter present the following sets of findings categorised according to the modification of the original depiction of Axford's (1995) conceptual framework, that is in respect of the ACP process in relation to inputs, throughputs, and

outputs. The images of how ACP was implemented and the outcomes of ACP for residents, family members, and the RN in RACFs are projected in the conceptual framework for the implementation of ACP (see Figure 4 – 3).

## **4.1 Inputs**

The data collected revealed that there are several resources that were vital to initiate the ACP process, such as organisational policy and manual, Guidelines from the Department of Health in NSW, motivational grounds, medical condition as catalyst, and the expert nurse (CNC in chronic and complex care in nursing homes). Each type of resource is elaborated below. Narratives are not equal to excerpts, but are themes as evidence of how each sub-element emerged from the data collected.

### **4.1.1 Organisational policy and manual**

Each of the three RACFs that participated in the study had its own organisational policy that endorsed the concept of ACP and ACDs. This is an important sub-element of the ACP implementation process, as it supports and encourages the staff to think about end-of-life care treatment options for the residents and family members for whom they care.

In Amen RACF, a number of policies were found to promote ACP in this facility and there were manuals explaining what advance care directives were about and when they should be completed. It was clearly mentioned in the policy under the section of ‘dying and death’ that RNs, the Director of Nursing (DON), and Assistant Director of Nursing (ADON) had the responsibility to respect residents’ rights and wishes with regard to dying and death. The policy directed these staff to initiate discussion with residents with regard to end-of-life treatment which must be sought at the earliest most appropriate time, and should include: active intervention, transfer to acute care hospital, palliative care, passive care, cultural and/or spiritual considerations, any other preferences and wishes with regard to dying and death. The policy also guided the staff to seek the expressed views, wishes and intent of residents and families, which were then documented in each resident’s integrated progress notes and care plan.

In this RACF, full consultation between the resident and/or her/his representative, nursing staff, doctor and/or palliative care team were promoted in planning end-of-life care. The

staff members were encouraged to increase the knowledge and skills needed to ensure the resident's dignity, privacy and peace.

There were policies in place in the Amen RACF that promoted individuals' autonomy in relation to end-of-life wishes. These were:

- The dying resident has the right to be as free from pain and other symptoms as possible.
- All wishes are met as far as they are legal and practical.
- Resident has the right to make decisions concerning care and to die as far as possible in peace and dignity.

There was a section called 'Advance or Anticipatory directives' in the manual in this organisation. It stated that this would allow people to make their wishes known regarding future possible medical and palliative care in the event that they were incapable of making decisions themselves. It was advised that such documents should be completed prior to illness or admission and that all family and staff were familiar with the resident's wishes (Amen Long-Term Care Manual, 2002).

In Christ Heaven RACF, there was a protocol for ACDs and Plan of Treatment (POT) in this RACF. The protocol provided definitions of ACDs and POT. It also included how ACP was incorporated in the admission procedure.

In this facility, an ACD outlined a person's wishes, should the time come when s/he was no longer able to consent to treatment for her/himself. In the absence of an ACD, or if a resident lacked the capacity to complete one, the 'Person Responsible (PR)' could complete a POT. The POT outlined treatment wishes in the event of a life-threatening illness and provided guidelines regarding the aims of the treatment.

On admission, residents and/or their representatives should be asked if they had an ACD or POT. There was a procedure in place for the cases when a resident did/did not have one, which will be explained in the next section. The protocol also recommended the staff to contact the CNC if residents or their representatives requested assistance to make an

ACD or POT on admission. Another protocol for using an ACD or POT was explained step-by-step for the staff to use in the event of deterioration in the resident's condition:

1. Contact the GP/after-hours service
2. Contact the PR
3. Consider how treatment options documented through ACP can be provided in the facility
4. Treatment options for reversible/irreversible illness may differ. Naturally, it may not be clear whether the illness is reversible or irreversible. In the absence of a current diagnosis, assume that it is reversible.
5. If after-hours/weekend, or GP service unable to attend, the transfer to hospital may be necessary to gain a diagnosis.
6. Call Community District Ambulance (CDA)
7. Complete hospital transfer form
8. Attach ACD or POT
9. Treating doctors at A & E Department will provide diagnosis and initiate treatment, in consideration of options documented. Referral to the appropriate service (PACS or Palliative care) will be made for follow-up at the facility as soon as possible.

(Anglicare, 2004)

In Evergreen RACF, the concept of ACD was supported in the policy and the procedure for ACDs pre-/on admission and at end stage was in place, although the terms used were various such as Advance Care Health Directive, Treatment Plan, and Advance Plans of Care.

The goal of the policy stated that each resident would have the opportunity to develop an Advance Care Health Directive or, where the resident had lost the capacity to give consent, a Treatment Plan could be designed between the family and the health-care team. To assist staff supporting families through the palliative care stage of a resident's illness, the formulation of a Treatment Plan eased the decisions regarding end-of-life issues and reduced the trauma of unnecessary hospitalisation. It also stated that the staff would discuss wishes for 'Advance Plans of Care'.

On pre-admission

- DON or her/his representative discuss issues surrounding advance care plans at the initial enquiry interview
- Relatives are informed of the publication 'My Health, My future, My choice'.

On admission

- Instructions for end-of-life decisions are documented on the resident information sheet if already made
- Staff encourage the person/persons responsible to start to consider advance care directive options for their loved ones
- Staff offer support and counselling.

At end stage

- Staff offer support and counselling
- Consultation with family and health-care staff
- Referral to the CNC for specialist care, palliative care, chronic and complex care at Prix Hospital
- Offer single-room accommodation.

(The Benevolent Society, 2005)

Person/s responsible were asked or encouraged to put in writing any advance care directives made for the resident. Document was placed in the front of the resident's folder and documentation was made in the nursing progress notes that it was received. Wishes were communicated to staff during report times.

As mentioned previously, in the document review, each RACF had its own policy and manual/protocol for ACP and ACDs. These were important sub-elements revealed by the participants about the ACP process and projected as a theme in Narrative 1.

**Narrative 1: ACP was included in our organisational policy and manual, and the nursing staff are supported to do it (ACP).**

The staff members at managerial level were aware of their policy and manual for ACP and ACDs, and strongly believed that the organisation's policy and manual were vital for them to implement ACP. Rosa said:

*They (our organisation) are very much into Advanced Care Planning. Yes I am aware of their procedures...//... Yes **there is a manual** ...//... They have a big team in head office that deal with all these matters which is good ... We need them **(the policy and manual) to do the right thing** (RN 10: Rosa: DON 1).*

However, the RNs who provided direct care to the residents were not aware of the policy and manual in their facility and requested a formal policy and manual on ACP and ACDs. The RN Donna was aware of the manual for palliative care but not for ACDs in her organisation.

*We've got a, **there is a palliative care manual**, and that's probably in there but I couldn't tell you verbatim what it says ... and that's it* (RN 4: Donna).

ACP, ACDs and POT were included in the organisation policy and manual only after the expert nurse commenced implementing the process of ACP in RACFs in 2001. It has certainly been an important sub-element for the facilities to take a more active role in ACP for their residents and family members.

#### **4.1.2 Department of Health Guidelines**

The guidelines for ACP and ACDs have been developed by the NSW Department of Health and it was important for the CNC to work within the guidelines, as they provided her with the standards to meet and the safeguard for her work. Although there was no legislation for ACDs in NSW, the CNC and each facility believed that the guidelines would protect them from litigation if there was a dispute with regard to ACDs.

**Narrative 2: There is no legislation but there are guidelines.**

One of the publications by the Department was called ‘Using advance care directives, NSW’, published in 2004. The purpose of this guideline was ‘to provide advice to health professionals on the best practice use of advance care directives within an advance care planning’ (p. i). The CNC worked as a member of the Advance Care Directives Working Party to develop this guideline and contributed to development of the documentation standards, which are specificity, currency, competence, and witness. These should be satisfied before an ACD was considered to have sufficient authority to act, therefore, it was important for the CNC to ensure that these four standards were met to proceed with ACP and for any ACD to be effective:

- Specificity – it must be clear that an advance directive applies to the clinical circumstances arising. The ACD should be clear and specific enough to guide clinical care that can include treatment preferences in relation to conditions existing at the time the ACD is made, as well as future anticipated conditions.
- Currency – an ACD prepared a long time before it is referred to may not reflect the current intentions of the patient. Nonetheless, if the person was competent at the time the ACD was made then it should still be treated as legally binding. People should be encouraged to review their directives periodically, for example, once a year, after an illness, or with a change in health, as treatment preferences may change accordingly.
- Competence – the person must have been competent to make her/his own health-care decisions when the advance directive was drafted. A person should be considered competent to make a health-care decision if s/he appears able to comprehend, retain and weigh up the relevant information and then make a choice. Some situations may pose particular difficulties in assessing competence to make an ACD, such as early dementia or intermittent mental health problems. A second opinion from a suitably qualified health professional is advisable.
- Witnessing – it is not essential to have an ACD witnessed. However, there are a number of reasons to encourage a person to do this. It may allow for later follow-up if doubts are raised about the person’s competence at the time of drafting. It offers some protection against forgery. It may also allay concerns about undue influence in the expressed treatment choices. If an ACD is completed in



conjunction with the appointment of an enduring guardian, then the witness may only be a solicitor, barrister, or registrar of the Local Court. If a 'stand-alone' ACD is prepared, the person may select who s/he wishes to witness the document.

(NSW Health, 2004, p. 7).

Another publication was called 'Guidelines for end-of-life care and decision-making' and also published by the NSW Department of Health in 2004. These guidelines replaced the 'Dying with dignity: Interim guidelines on management (1993)'. The CNC adopted these guidelines as fundamental foundations, as the goal of this guideline was to promote communication, compassionate and appropriate treatment decisions, and fairness, which will result in safeguards for both patients and health professionals.

#### 4.1.3 Psychological catalysts

This sub-element concerns the grounds on which the staff initiated the ACP process and what motivated them to initiate the discussion with residents and family members about end-of-life care treatment options. There were two distinctive motivations that worked as psychological catalysts for staff action: 'to identify what they want', and 'to give the older person and the family the right to decide'. This finding is reflected in the following narrative.

##### **Narrative 3: We need to know what they want, as they have the right to choose**

The fact that the staff were unsure about what the residents or family members wanted in relation to their end-of-life care motivated them to initiate the ACP process. They have expressed what it was like to be left to wonder what an older person might and might not want. The possibility of doing something that was not wanted by the person has led Carla and other RNs to seek what they wanted through the ACP process.

*... sometimes **we don't even know** people's death wishes when they die ...//... I am not sure if that, if what stage they had a stroke or a heart attack, they didn't want any intervention, or if they had cancer they didn't want surgery ...//... we often if somebody is sick, we say to the doctors like, what do you want us to do, what does the family want? And they say, I don't know, sometimes they (doctors) say **they don't know and it really worries me** too, that we can send them to hospital or give them treatment they may not want. Or if we don't do it and they want it...//... At what level do we manage*

*them here or if they get other conditions with it like pneumonia or ulcers, like ... what do they want? We can put drips in and things like that, but how do we best manage them? Do they want it conservatively, palliatively or aggressively and that's where **we don't really know if we are doing what they want or what the family wants. We need to know** and I kept harping and harping (to do something about it) because, you know, we don't know. Sometimes that is the frustrating bit because you don't really know if the person wants antibiotics or if they want to have alternative treatment (RN 3: Carla).*

Another motivational ground for the staff was 'to give the old person and the family right to decide' through ACP. There was a strong belief that the residents and family members had the right to decide and the staff as health-care provider only had a duty to follow. It was important for the staff to be aware of the rights of the residents and family members to decide. This mindset worked as a motivational ground that promoted the implementation of the ACP process. Katrina and Wilma shared their thoughts on what motivated them to initiate the ACP process.

*It (ACP) is not telling them what we would like to do but it is **asking them what they would want us to do** (RN 26: Katrina).*

*I think that, I would say, you have **a right to decide how your life ends. You have a right to decide what you do and you don't want**, just like Dr Malone said, why should, why should we decide for somebody else what they want when we wouldn't want that to happen to ourselves? (RN 7: Wilma: DON 2).*

#### 4.1.4 Medical catalyst

It was interesting to observe that not all residents or family members were approached to have a discussion about ACDs. There were certain conditions or criteria that the resident presented in order for the staff to initiate the ACP process. This sub-element involved medical conditions that worked as catalysts for the staff to initiate the discussion about end-of-life care treatment options. This sub-element was well supported by the staff across all facilities, which is evidenced in Narrative 4.

#### Narrative 4: They have to deteriorate to be offered ACP

The most prominent reason for which the staff initiated ACP process was 'deterioration in physical health and frequent hospitalisation'. Wilma said:

*When we are talking and the staff will say, 'oh **this person is deteriorating**' and if they haven't got Advance Care Plan that will be a signal to raise the issue again. ... //... So some of them express their wishes not to be sent to hospital or they get sicker then that triggers you to okay, we have got to do something (RN 7: Wilma: DON 2).*

It means that the staff felt uncomfortable and that it was unnecessary to discuss ACDs when a resident did not show signs of deterioration but did seem to enjoy life in the facility and was happy with the care provided. For example, Rosa mentioned that:

*Like these residents here, there is nothing that will indicate that they need Advance Directives because it's not like they have only got three months to live, you know, some of them are here how many years, you know what I mean, so can't see them ... because **they haven't even been to the hospital** (RN 10: Rosa: DON 1).*

Another catalyst that was important to the staff in commencing the ACP process was the perception that the older person was 'suffering'. No matter if it was the resident or the family member who was experiencing suffering, the staff would initiate the discussion about ACDs in order to reduce 'suffering'. For Krys:

*It is usually that the word suffering comes along, **I don't want mum to suffer**. I don't want tubes, so they give you a bit of a hint ... //... Well, they might say that they are not sure how mum is going to go and we don't want her to suffer. That's the beginning when they say, when we say what do mean by that (suffer)? What sort of care do you think we could do for you so that mum doesn't suffer? So you start then and that sort of starts them off. Because they will say we don't want her to be in any pain ... (RN 23: Krys).*

A catalyst that prompted the family members to express their willingness to discuss end-of-life care options for their loved ones was a 'negative experience in the hospital'. It was experienced by the family members that the older person was left in an A & E Department without being properly assessed and apparently regarded by the A & E staff as untreatable. As a result the sick older person was returned to the facility. This caused the family members to reflect and realise that hospitalisation did more harm than good for their loved one, and that there was the need to prevent their loved one from being hospitalised and the need to make this wish known. Tess felt that:

*The hospital already know, **they (the hospital) don't really want him to come back**. He is a pretty sick man. The hospital already know, they don't really want him to come back (FM 8: Tess).*

It was not until the residents presented to the hospital frequently and their health deteriorated, causing suffering to family members that the nurses would initiate the discussion about what sort of treatment residents would and would not want. Therefore, advance care directives would not be completed in advance but at the very end of life. For this reason, it was often the case that the residents were often not able to express their end-of-life wishes.

#### 4.1.5 The CNC

With the acknowledgment of little or no knowledge of nursing home residents' and their relatives' wishes for end-of-life treatment preferences in the event of deterioration, one senior nursing position was funded by NSW State Health under the Chronic and Complex Care Program Project to pilot and trial the use of ACDs to residents of aged-care facilities in 2001 (Caplan et al., 2006). The service was aimed at those residents receiving high level residential care, residing within one of the area health services in NSW, Australia. The objectives of the CNC were to:

- develop the concept and framework for implementing ACDs for those capable of completing their own directive
- develop an alternative for those residents who had lost capacity, and substitute decision-making was required
- reduce Emergency Department presentations from residents in high-level RACFs
- reduce hospital admissions from residents in high-level RACFs.

#### **Narrative 5: She has been like a white light**

The CNC was an integral part of implementation process of ACP in RACFs and appreciated by many RNs, as projected in Narrative 5. It was reported that if there was no CNC, then there was no ACDs documented. The CNC was dedicated to the promotion of ACP where there were a state of readiness, as was shown in the previous narratives. Carla expressed how she felt about the roles of the CNC in ACP.

*... if families want to have discussion with somebody they are happy for us to ring say, Hanna (CNC ACP), and organise it ... she has been like a **white light** that has come in and is **having conversations with residents and getting things documented** ... the*

*DON must have coordinated an appointment so she (Hanna) came out and spoke to him and he expressed, ... they talked to him about how things were and what things he wanted and didn't want and things like that (RN 3: Carla).*

Donna said:

*If any resident wishes to document it (ACDs), it always has to be **Hanna comes in and makes it formal and document it**. Definitely, we always ring her up to tell her. We ring up Hanna, she will say get the referral, we fax the referral over to her (RN 4: Donna).*

Wilma expressed how important the CNC was in the implementation of ACP in her facility.

***I make referral to Hanna**, yes. I don't always ... Sometimes the staff out in the ward say like Heather or somebody else will do, oh they (residents) said, they said, they don't want to go back to hospital, they don't want any more treatment or they don't ... And I will say, okay we need to get Hanna involved (RN 7: Wilma: DON 2).*

It was clearly noted that the expert nurse played a significant role in implementation of the ACP process in the RACFs. The expert nurse was a vital resource for the staff in RACFs to set up a process in order to identify what the older person or family member would want at the end of life and what they would need to make decisions for themselves by themselves. Usually, this conversation did not eventuate to documentation of treatment preferences until the resident experienced deterioration in physical health and made frequent hospital trips. The staff members in facilities were able to take the voices of residents and family members into the policy, manual and nursing care plan, and to minimise suffering by identifying what was wanted and not wanted. They were also encouraged and supported by the Guidelines developed by the NSW Department of Health (2004) to provide the level of care wanted by the older person and family members. The following section now describes what the expert nurse and the nursing staff in the facilities needed to work with and through in the ACP process.

## 4.2 Throughputs

The process involved for ACP in RACFs centred on the management of 'throughputs'. There were 10 sub-elements included in 'throughputs' that the staff needed to work with or work through in the ACP process and these are described as follows.

### 4.2.1 Guardianship Board

When Hanna commenced the ACP project she had encountered a hurdle. She realised that there were not many older people in RACFs who were legally capable of executing their right to choose treatments in ACDs. The strategy that she took in order to deal with this issue became evident in Narrative 6.

#### Narrative 6: Families of incapable residents can do a POT

It was inevitable for her to expand the concept of ACP from the one that was previously limited to capable older people to the one that would include incapable older people and their substitute decision-makers. For this reason, the Guardianship Board became one of the essential sub-elements that she had to work with in the process. Hanna explained:

*When I started Advanced Care Directives, was going out and trying to find capable people to do a directive with, but it was pretty you know, within about three months it was fairly evident that we needed an alternative mechanism. To be up front and actually do that with families and it was through searching on Advanced Care Planning and doing a search on proxies and stuff ... //... That there weren't enough people who were autonomous to do that (ACDs) but what was, within three months, what was clearly the need, probably a bigger need, was that we needed **a process to work with substitute decision-makers** (RN 25: Hanna).*

She took this matter to the Guardianship Board and an alternative was suggested by the Guardianship Board, that a Plan of Treatment (POT) could be done by the Person Responsible (PR).

*... they (the residents) needed to be capable to do a directive ... But it was sort of fairly evident that nursing homes, their concerns were that families drive all these sort of discussions and they override the resident and they (the family) dictate what will happen. And it was almost like well you've got to work with that, so we went to the Guardianship Tribunal and said 'Well can the family do an Advanced Care Directive?' and they were pretty clear that it wasn't a very autonomous thing for the Person Responsible. Their words were **'the person responsible can indicate in a Plan of Treatment what they would or would not agree to in advance'**.*

*So it sort of put an obligation on them (family) to start thinking and talking about what sort of problems or difficulties we could anticipate and how we might manage those and start having that discussion with the person responsible, and having facts then, sort of, same definitions for a directive but clearly putting it in the context of this is the person responsible that we have tried to draw out from them **what they understand***

***the resident's values would be, that they can't consent to special medical treatment. We sort of put some provisos in there*** (RN 25: Hanna).

The Guardianship Board was one of the sub-elements that not only the CNC but also the RNs needed to work with in ACP and this was reflected in a manual developed by the Amen RACF for the nursing staff with regard to cognitively impaired residents and the Guardianship Board application process. The following is an excerpt from the manual (Amen Long-Term Care Manual, 2002).

*Where a person has lost their mental capacity and can no longer make an advance or anticipatory directive for themselves, an application may need to be made to the Guardianship Board on their behalf. The Guardianship Board is a tribunal that has the power to appoint legal guardians, to give or refuse consent to medical/dental treatment for persons who have lost their mental capacity and for whom informal arrangements are not working.*

The RN Mia in the Amen RACF shared her experience of working with the Guardianship Board in the ACP process.

***A Guardianship is, some residents if they don't have anybody or if they don't have a next of kin or sometimes they have children but they want to give their guardianship a role, so we tell them and the resident, if they can talk, they take the resident to the Guardianship Board. Otherwise they come here and talk to them about the will, about financial things, everything. And then, with the guardianship even, if they have children as the next of kin and we have a **Guardianship Board** ... any changes of their condition we have to let them know as well*** (RN 2: Mia).

#### 4.2.2 Documentation

Documentation refers to the paperwork that all the participants involved in the ACP process needed to complete and that would facilitate the ACP process. It included the Mini Mental Status Examination (MMSE), Geriatric Depression Scale (GDS), Value Clarification, ACP Nursing Assessment Form, the Admission package in each RACF, ACD form, and POT form. How these documentation systems became a part of the ACP process is projected in Narrative 7.

### **Narrative 7: Documentation was embedded in the process for incapable residents**

The ACP was the process that facilitated discussion about what treatment an individual would or would not want when s/he could not speak for her/himself any longer. It was believed that the capacity to express who they were and what they were was a crucial prerequisite to advance this process. One may request ACP to shorten her/his life by refusing treatment options that promote well-being, due to depression or social isolation. There were cases that the CNC did not progress to ACP but she did refer the older person to a psychologist or psychogeriatrician. Therefore, it was essential for the CNC to perform cognitive and psychological assessment on each individual in the initial visit.

MMSE was used to assess the cognitive ability of an individual who was referred for ACP or who wanted to document ACDs. The older person was considered as capable of expressing end-of-life care treatment preferences if s/he gained 16/30 in MMSE as advised by the regional AHS. Hanna explained:

*Well if they were really able to understand and sign ... Say for instance their minimal score was quite high, then I would say 'Do you know, are you aware that there is a process that you can go through so that if you end up bedridden or not able to feed yourself, whatever, that you can have, your wishes can be respected by medical and nursing staff'. Yes, I would say that but I think I would really have to try and **assess them first** so that I didn't frighten them (RN 25: Hanna: CNC).*

In case an individual wished to document ACDs, the CNC or the staff in the facility assessed whether an individual was influenced by depression, using the Geriatric Depression Scale (GDS). Given that there were some people who suffered from depression and who believed that they could refuse or limit treatments to shorten their lives or to hasten death through ACDs, it was imperative that the individual was not under the influence of depression. The result of the GDS assessment was important, as it provided the RNs and the CNC with a safeguard that they were not helping someone with depression to refuse treatment that they were entitled to or that ACDs were misused.

The staff and the CNC also needed to work through other forms of documentation in the process of ACP. For example, the questions regarding whether an individual had an ACD or wished to document one were included in the admission package. However, this change



was not embedded in the admission package until the CNC was involved in the process. Hanna explained what and how she approached the facilities:

*We asked the nursing homes to identify who would be the person responsible for this process, for this patient, current residents, and then we said 'Now we need a new admission (process) to identify the person responsible, in your pre-admission paperwork', and that was setting up the process for, I guess, So you've got your current group who are in, and who is the person responsible?... When they are coming in (to the facility), to put in that person responsible information sheet, **to identify the person responsible at admission, that was embedded in the process** (RN 25: Hanna: CNC).*

There were three facilities that participated in the current study. Each facility had its own admission package, therefore the questions with regard to ACP and ACDs were reflected in various ways. There was a Yes/No tick box for Christ Heaven RACF, asking if the new resident had an 'Advance Care Directive/Plan of Treatment'. It was also noted that the details of the PR needed to be provided in the admission record. There was a form called 'Declaration by person acknowledged to be client's representative and PR'. The rights and responsibilities of the PR were explained in the form and the PR needed to declare that s/he understands and accepts her/his rights and responsibilities. There was another form called 'Getting to know you' for Christ Heaven RACF. This form was to be completed by the prospective resident or her/his carer prior to admission to Christ Heaven in order for the staff to help understand and care for the resident. It was clearly stated on the form: 'has the resident made you aware of their expectations regarding end-of-life care?, and if yes, please specify in the space given'. With the formalisation of asking about ACDs, the nursing staff needed to work with the question or the form included in the admission package if an individual had an ACD. Wilma reported how she approached a gentleman:

*Sometimes **on admission** like that gentleman, **I approached it with him** and he has since gone home, but I did approach it because he was saying words like, I want to die and that sort of thing. I am saying to him, well have you made plans, what do you want to do? and he didn't really know. So I was able to initiate it there. Other people might approach me so I then take it on board and I ring, the Hanna who we liaise with, I do that (RN 7: Wilma: DON 2).*

For Evergreen RACF, there was a form called 'Admission sheet' and it was filled in by the RN who admitted an older person. The RN needed to circle 'Yes/No' for 'End-of-life decisions made' on the admission sheet and to state 'information held by whom'.

Interestingly, it was found that none of the residents in Evergreen had their end-of-life decisions made in an ACD at the time of admission. However, it was noted that there were seven residents out of 47 whose family members made a statement in a confidential letter sent to the DON with regard to wanted/unwanted treatment some time later after the admission. Suzie explained the documentation system in her facility:

***On our admission form we have ... we ... just like a simple questionnaire, is end-of-life decision made, yes or no and information held by... and the funeral arrangements. So we have got that and we attach that to our form. So that is about all we have on admission and then we just progress from there and ask them to follow up*** (RN 24: Suzie: DON 3).

A gap between the policy and practice with regard to ACP and ACDs was noted. In Amen RACF, there was no question to address whether the older person had ACDs in the admission package, although the policy and manual strongly endorsed the concept of ACD.

#### **Narrative 8: Documentation was a tool to find out ‘who the person is’**

Another important form of documentation to work through was the ‘Values Clarification Worksheet’ and ‘ACP Nursing Home Project Assessment Form’. The CNC mentioned that it was essential for her to assess what an individual valued in life while she went through the questions in the forms. She believed that people would make decisions based on what they valued and what they would/would not tolerate in life. It was also important for her to find out how an individual dealt and coped with a crisis in life, as this information would provide her with an insight about how the person felt about what was going to happen at the end of life. Hanna explained what these two forms of documentations meant for her:

*In fact the family get to say ‘Well you know, mum used to be like this and she ran around the house and did this, and she worked, she painted’ You hear all this great stuff about who mum was and hearing that **it helps me sort of phrase a little bit**. It is well, it sounds to me like your mum was really independent or your mum really, liked to listen to other people or she liked to give opinions on things or she liked to listen to the radio or she liked music or all that sort of stuff that they liked before, but also **how they made decisions before** ... when your father died, what did she, did she ever make any comment about that was a good process, you know, it was good because it was quick, or it was good because it was peaceful or it was bad because it was quick, or it was good for him but bad for us because it was such a shock and ... That probably helps reconcile a little bit because you, in sort of an abstract way, **getting their perceptions about what is a good or bad death** ... //... and reflecting on that so they can sort of*

*gauge from that. Or maybe when they moved house or if they changed jobs, like how did they approach those decisions, were they just really sort of pragmatic and go 'no that's it, I am doing it' or did they seek people's advice or talk to, you know were they really inclusive in conversations or seek expert opinion? **How did they approach sort of major decisions in their life?** about you know, getting divorced or getting remarried or ..... moving house, planning different other events, family weddings or, yeah, selling up their home, those sort of big decisions that people have in their life that they have had to face before, placing someone else in residential care, providing care for someone. Just sort of what sorts of things did they talk about ... So **that would be a really rich conversation that one.... that's really important to me** ... Well if you didn't have that it would be just all about the document so ... I guess that helps my sort of satisfaction in hearing all that (RN 25: Hanna: CNC).*

The 'Values Clarification Worksheet' was considered as a tool to assist in the development of an advance care directive and was adopted from 'The complete life: Care of the dying' (United Hawaiian (UH) Center on Aging, 2002) in order to capture the information about who the person was and how s/he lived life that might help to give insight about the essence of the person.

The 'Values Clarification Worksheet' examined what the person believed about quality of life by asking specific questions about various levels of changes that may occur at the end of life in physical and cognitive functions, and ability to control those changes. It also provided an opportunity to explore what an individual would want:

- if I were very sick, told that I was to die soon, and that there was no reasonable hope that I would regain a quality of life acceptable to me
- if I were in a coma and the doctors thought I only have a slight chance of returning to my normal health.

The personal, ethical, or spiritual beliefs that an individual wanted respected in decision-making about life-sustaining treatments were also explored in the worksheet by posing queries such as the following;

- It is always wrong to withhold (not start) treatments that could keep me alive.
- It is always wrong to withdraw (stop) treatments that could keep me alive after they have been started.
- It is wrong to withhold (not provide) nutrition and fluids given through tubes, even if I am terminally ill or in a coma.

- I do not wish to receive a blood transfusion or any blood products, such as plasma or red blood cells.
- I believe that it is acceptable to consider the financial burden of treatment on my loved ones when making health-care decisions on my behalf.
- I believe that my loved ones should follow my directions as closely as possible.

The worksheet provided the person with a chance to express their preferences for surgery, Cardio Pulmonary Resuscitation (CPR), antibiotics, dialysis, respirator, ventilator, transfusion, artificial feeding via intravenous, nasogastric tube, or Percutaneous Endo Gastric (PEG) tube.

A 'Values clarification worksheet' was a comprehensive assessment to identify what the person considered as quality of life. It was also important to identify what the person believed as unacceptable or intolerable in life. 'ACP Nursing Home Project Assessment Form' was developed by the CNC to assess an individual's personal details (person responsible, accommodation type), past history (medical, social, services used, placement), past hospital involvement, current status (medications, symptoms, functional level, previous discussions, thoughts or wishes), resident's past experience in life, social relationships with others, religious affiliation, spiritual sense, faith/beliefs, familial concerns, hospitalisation/illness in the last six months, and issues for the future in need of consideration. When the CNC went through the processes, she focused heavily on who the person was, how the person lived life, and what s/he wanted at the end of life, as reported below.

*It is **people's values in their life, what's important, how they live their life.** So if you have got an idea of that, it is going to help the individual phrase what would be important to them, what would be tolerable or intolerable. So I think that's a good precursor ... //... **you need to know all that background to sort of shape other things or just be aware of factors in their life ...** // ... Well I think in going through a little bit of chronology in their life, where they have been, where they are at, what shaped their decisions as they have along, and that's what will help ... //... **The past experience is probably a good predictor of, you know, future performance, therefore, future decisions. It will be consistent with the way you have lived your life ... it is just trying to explore ways around what's important to them, what gives meaning to their life, what's important in their life, what's not important.** For some people it is their showering or the dependence or physical things. With other people it is their thinking, their interaction, like just trying to draw that out, it phrases questions for different scenarios, I think it is fairly comprehensive in that it gives lists of things. So it **helps me think through systematically for everybody, this is my approach so I find that that's quite comprehensive** (RN 25: Hanna: CNC).*

There were some questions that purposely contained double negatives or were a bit long, in order to clarify and spell out exactly what was wanted and what was not wanted. Hanna said:

*I think it (Values Clarification form) is a bit long, the form itself is too long, it is a bit tedious, you know, and yet in all that tediousness, and the phrasing of that can sound a bit ambiguous so people actually have to think about it, some things in the negative, so they're going 'What do you mean by that?' So **actually encouraging them to talk it through a little bit.** Well yes I agree with the statement that it would, it wouldn't be wrong to withdraw this, so it would be okay to withdraw, yes'. So it is actually getting that a lot clearer than just saying is it wrong to withdraw treatment, yes or no. **They go 'no' you know. But if you get them to tease it out and say 'What are you actually saying there this question is confusing?' In some ways I think it is deliberately confusing to make you draw it out** (RN 25: Hanna: CNC).*

Therefore, the CNC believed that she must work through this assessment to work with the individual and their significant family members.

Another form of documentation that needed to be worked through in the ACP process was the 'ACD' for an older person who was capable of making decisions and a 'POT' for the PR if the older person was not capable of making decisions. These forms were filled in by the CNC only. The ACD form used by the CNC was modified with permission from the ACD (NSW version) developed by the Advance Care Directive Association Inc in 2003. The POT was slightly modified from the ACD form by adding information about the PR. The Narrative 9 reveals the nature of ACDs and POT.

#### **Narrative 9: The questions in ACDs and POT are comprehensive and extensive**

The essential contents of the ACD form included a statement from the person to define an intolerable situation, which was when the directive would take an effect. Then the person needed to state if s/he would like CPR in case either s/he had reversible or irreversible illness. Four different levels of care were explored with the person or PR and these were as follows:

- Palliative care aims to manage symptoms, including pain. Any investigations or treatments will be to improve comfort and decrease distress.

- Limited care includes palliative care, antibiotics, and limited investigations. It may also include treatment in hospital, if necessary. It does not include elective surgery except for comfort or pain relief.
- Active care includes limited care as well as all possible treatment, including operations. Breathing machine (ventilator) is used only for the purpose of surgery or recovery from surgery.
- Intensive care refers to active care as well as everything possible will be done to maintain life. If necessary, intensive care unit and all possible means of life support will be used, including surgery transplants and ventilator support.

It was clear that ACDs or POT were not simply about whether an older person would want 'CPR' or not, or whether the person should be left to die or suffer because of an 'NFR' order in ACDs. It was a fairly comprehensive way to explore the options for an individual and the consequences of the decisions made in case s/he could not make decisions for her/himself. The person or PR was asked what levels of care they would like in case they had a reversible or irreversible illness. They could make comments or special considerations in their own words to best express their wishes. Then the four levels of feeding methods were discussed with the person or PR what they would prefer among them. These were:

- Oral or basic feeding refers to food and fluids by mouth, being helped to eat and drink. No food via a tube or fluids injected into a vein.
- Supplemental feeding refers to oral feeding and additional vitamins, high energy and protein drinks.
- Intravenous (IV) feeding means that supplemental feeding and fluids and nutritional supplements are given via intravenous drip.
- Tube feeding includes IV feeding and a tube that may be through the skin and into the stomach (gastrostomy or PEG), or via the nose (nasogastric).

To be effective and legally valid, the CNC adhered to four documentation standards developed by the Department of NSW Health, as mentioned before. She assessed the capacity of the person and the PR, if necessary, using MMSE and GDS. The CNC discussed the end-of-life care issues and values in life as much and as specifically as possible in order to minimise misinterpretation of the written document and to capture the

best interest of the person. The ACD form required the signature from the person, PR, witness who was not a paid carer or beneficiary, and the CNC. She also made an entry to review the ACD to keep it current.

It was only recently that the CNC was invited to the Evergreen RACF in order to implement ACP. The usual practice of the end-of-life care decision-making process in the past in the Evergreen facility was leaving it in the hands of the PR or significant family member to write a statement in their own words of what treatment they would or would not want for their loved ones in this facility. Therefore, family members in this facility were not given the opportunity to discuss with Hanna the values in life, the way the older person lived her/his life, treatment options and the consequences of having/not having treatments. Suzie, as a manager in a facility, confirmed that:

*By Person Responsible, Enduring Power of Attorney and it is written in their own words what to be done, what is not to be done, and we just, **we want their directives, their own directives and we ask them to put that in writing**, yes, even if it is a letter you know (RN Suzie: DON 3).*

The documentation that nurses needed to work through in ACP was quite extensive and comprehensive. It was not simply about signing for 'NFR' or 'No hospitalisation', as some staff were concerned about in the early stage. The documentation that they worked through was a tool to ensure that no one missed the chance to promote health and well-being even, at the end of life, and that no one misused ACDs to shorten life or hasten death.

#### 4.2.3 Case conference

The case conference was the third sub-element that the CNC and the staff needed to work with in ACP process. As mentioned earlier, deterioration in health and frequent hospitalisation were the reasons for calling for ACP which prompted the conversation about future care options between the people who were interested in the older person's well-being. The meaning of having a case conference was revealed in Narrative 10.

### Narrative 10: All will be discussed in the case conference

The case conference was a formal approach in which this conversation occurred and was organised by the staff in the facility. The people who were invited in for a case conference were the resident, family member, the RN, the AIN who provided hands-on care the most, the DON, GP, the CNC, and the palliative care team. Heather explained about when she would call for a case conference:

*When a resident makes frequent hospital trips or their health is getting deteriorated very dramatically and there is nothing you can offer any more, then you **call for a case conference** with everyone involved and discuss, how, what they can do to make them comfortable and pain-free (RN 5: Heather).*

The case conference also provided people with an opportunity to express their feelings and concerns with regard to what they were going through and what could be done. Families usually accepted the fact that it was time to discuss end-of-life care for their loved ones and that it was time to make decisions. Donna believed that:

*Case conference is good in a way where you get to **bring out their innermost feelings**, what they want for their loved ones. Yeah. Because sometimes if you don't sit down and discuss, you don't bring it out. And then they get unhappy and then they become defensive (RN 4: Donna).*

The case conference was a way to get people together in order to make decisions for the resident, based on what the older person would have wanted and the decisions were not made until they addressed what have been done, how it affected the resident, and what it meant to have or not to have further treatment. The case conference aimed to discuss what options there were and what would be acceptable for the older person. Heather said:

*So once you get to the actual case conference then people have more or less ... You start at the beginning, we want to, we have the case conference, the aim is to decide how to proceed in the future if Mr X or your husband gets a chest infection or has a stroke or has a heart attack you know, we want to **discuss what options there are for him and then come to the decision between us what's acceptable for him, what would be most acceptable to him.** The family usually have an idea of what their husband would want, or their dad or mum would want, so you know **'he wouldn't want to be resuscitated** if he had a heart attack, I know that, he said so in 1962 (RN 5: Heather).*



Given that the issues they discussed in the case conference were sensitive and comprehensive, it required a sensible approach for the staff to proceed in the discussion. Understanding the older person and the family made the difference in case conferencing to reach consensus in decision-making. Narrative 11 disclosed how nurses contributed to case conferences.

### **Narrative 11: Nurses know how to help people in case conferences**

The case conference was not a rigid static event, as each family was different in how it approached the issues of end-of-life care in the conference and how it had made decisions in the past. There seemed to no one magic ingredient for the staff as to how they should approach the people in the case conference, but it required a person-centred approach for each individual and family. Krys thought:

***It depends on the person, everyone is different.** Like some case conferences you start, it is immediate when you go in, the family 'I don't want them to go back to hospital any more' and that's it, I mean and they are really short. But then other ones it can take oh half a hour, an hour to get around to actually saying 'so do you want the person to go to hospital if they get sick or in which situation would you want your husband sent to hospital or in which situation would you be happy for us to treat him here?' So it varies, people are so different in how they react to things (RN 23: Krys).*

However, it was evident that nursing staff in the facility were in the best position to apply an individualised approach and to be successful, given that nursing staff had built a relationship over the time with the older person and family members. Not surprisingly, nursing staff engaged in the relationship with the older person and the significant family members in the facility for a long time were persistent enough to gauge what this particular person and the family would want at the end of life. Krys said:

***You sort of have an idea I think and talk to the families.** Before you even have a case conference it is all discussed anyway, but then the case conference is the formalising it all ... //... usually the family ... you already talk to the family, you talk to the families all the time about various things. Usually **you would have a pretty good idea what their feelings on the subject are** from things they might have said in the past 'Oh I wouldn't want my husband to be like him' or things like that. You can get ... by the time you have actually organised to have a case conference, there is usually some sort of an agreement hanging around in the air already (RN 23: Krys).*

Although there was a consensus on the benefits of having a case conference to discuss treatment options and consequences, the initiation of the conversation did not happen until the older person reached the end stage of life and not everyone was given this opportunity, as mentioned previously. Therefore, there was a call for a systematic approach in the case conference. Wilma suggested:

*How it should work is that, what we should be doing is **having at week six, having a conference with the family** and then we should be able to raise that (advance care directives), because on the conference record it actually talks about Advance Care Planning ... // ... we have got another piece of documentation now that is an actual conference record of talking to the family. And we are supposed to do that at week 6. That's the record we are supposed to use at week 6 which would then assist us to fill that (Advance Care Directives) in (RN 7: Wilma: DON 2).*

#### 4.2.4 Discussion

Discussion is another sub-element that the staff and the CNC needed to work through in the ACP process. It refers to the conversation that occurred with regard to ACP and ACDs between the resident, family member, GP, the CNC, RN, AIN, and other health-care professionals as necessary. The discussion occurred during the case conference, initial visit to the resident or the family member, or even in the corridor informally, if that was what the family wanted. The staff in the facility were willing to listen to the residents and the family. However, if the staff felt that the family needed or wanted to talk to someone who was more experienced and qualified, they organised a formal discussion with the CNC, as Heather said:

*If families want to have discussion with somebody they are happy for us **to ring say, Hanna, and organise it** (RN 5: Heather).*

#### **Narrative 12: Discussion is about giving people choice, full information, and counselling them**

Discussion was about giving people choice by explaining what could be done in the facility and what the different levels of care were, so they could make an informed decision. Wilma said:

*We **give them a choice**, we **give them a choice**, but we try to explain to them unless absolutely necessary, they would be better looked after here. And so you go from that level and then you might jump to the next level and say ‘Well do you want active or limited care?’ And then you go to the next level ... (RN 7: Wilma: DON 2).*

It was also important in discussion to see what the resident’s or family member’s understanding was about the prognosis of the illness and the consequences of having or not having treatments. Hanna reported:

*To see if you’re on the same pace sort of thing. (To) talk about what we can and can’t provide or try then at that point, try and draw out **what their understanding of what the patient would be** thinking and saying. That’s sort of a hard process for them as well too. Because often they don’t know what they are thinking or saying. Then I might start talking about what sorts of treatment and **what they do or don’t want, what the benefits and burdens might be** (RN 25: Hanna: CNC).*

Discussion provided the staff with justification and legitimacy for their nursing-care activities. Staff were not willing to do anything not discussed with the family and were willing to discuss anything at any time. The discussion might not necessarily be formal, like the case conference, but could happen in the corridor or in the dining room. This informal discussion between the family member and the nursing staff had an important indication in that it was a part of the process to prepare the family members mentally and intellectually step by step for what could be a shock and unknown to the family member.

Discussion did not necessarily mean simply a conversation about end-of-life care options and making decisions, it was also about reassuring and counselling the family members in order to help them get through at the end stage of life of their loved ones. Suzie said:

*We try to get everything set in place and **we reassure them (families) and we counsel them** because a lot of ... Because our relatives are so old also, it is very hard for them even to want to think about it because a lot of our spouses, they’ve been together for 50 or 60 years, you know it is a long, long time and they’ve just adored each other for all of this time and it is very, very hard, particularly with the men. And the men I find do not have the ability to accept what’s happening to their spouse and they are always thinking they are going to get better. So it is reassure [sic], it is education and it is just **counselling them through** the whole period (RN 24: Suzie: DON 3).*

It was important to make sure that everyone was involved in the discussion and worked towards the same goal, which was to achieve what was best for the older person. The discussion process helped people by taking off the load to make the sole decision. The

decisions that were needed to be made in discussion were whether to send the older person to the hospital or not, whether to provide the older person with active or palliative care, whether to resuscitate the older person or not, and whether to provide the older person with artificial feeding through IV or tubes. These issues were not simple, but complicated, and could be emotional. Whether it was a family member, a doctor, or a nursing staff member, they were uneasy about being a sole decision-maker, rather they would prefer to be conjoined decision-makers, as they could support each other about the decisions made and the consequences of the decisions made. As Krys said:

***It is imperative that everybody is on board about it, so the family want the same things as the doctor and the nursing staff, so that everybody is comfortable with how they are doing it. And if everybody feels comfortable then it will work really well. If people are comfortable with how it has gone and it is all, the process is set out for them so that they, they feel, they are not making a decision. That's what people find the hardest thing to do is to make the decision. So the person who has the decision in the end, is not actually having to make one, then it makes it much easier for them to decide what to do ... // ... It is the same process really, that you get everyone's agreement to what's, what's going to be, to happen to the person ... // ... When there has got to be a major change of the planning, the care planning of this person then you want everybody to be well informed about it, the reasons why. You know it can take an hour and half, even longer, to, to have this meeting but it is worthwhile in the end*** (RN 23: Krys).

### **Narrative 13: Discussion should promote conversation and explore possibilities**

It was ideal if decisions were made clearly during discussion by everyone involved. However, having something documented was not the main goal of the discussion. Besides, there was a possibility that some might not follow the decisions made without understanding and agreement on why the decisions were made. As Hanna said, discussion was a tool to identify who the person was, what the person would like, and what the best option was for the person.

*Like some families we have talked about CPR and level of treatment but the whole idea of feeding, they haven't really got their head around. So you can just walk through that, say well to be determined as the need arises or continue as is and you don't necessarily refuse anything, you just leave that blank for all those levels of feeding. So you are going yes, continue with basic feeding but you leave the others blank, well there has been no decision made here about yes or no ... // ... But it is at least working in the right direction I think **as a tool to having the discussion** and that in itself helps families* (RN 25: Hanna: CNC).

The discussion process rationalised the concept of ACP and it was a crucial part of the ACP process. The ACP process was not there to help people shorten their life but to promote or maximise quality of life up to right at the end stage of life. These goals were achieved during the discussion process by asking and challenging the person and PR with ‘why?’ and ‘what if?’ Without the discussion process, if the person was left to document whatever s/he wanted, the person could make decisions while s/he was depressed or the person might not fully understand the extent and the consequences of the decisions s/he was making. S/he needed to be empowered and educated to make their own decisions through a number of discussions, as it did not happen in one session. Hanna explains:

*You can write a document but if you are going to help someone do it (ACD) you want it to be a reasonable process ... // ... Yes she (a resident) did sort of have some concrete ideas about stuff and I wanted to make sure that I wasn't just going, ‘Okay well, you don't want this and you do want that’. It is like ‘**why but what if**’ and ‘**what if**’ and to sort of challenge them so that you are **not minimising their opportunity at life**, just because we've drafted some document (RN 25: Hanna: CNC).*

#### 4.2.5 In-service education

The CNC had provided a number of in-service education sessions to various groups of people, which was essential and imperative, as the concept of ACP and the use of ACDs were barely known to people who were involved in the care of older people when the CNC established the ACP process in the RACFs in this study. Staff who attended her education sessions were the staff from the A & E Department in the regional hospitals, GPs, nursing home staff, families in facilities, the PACS team, ambulance officers, and community care staff. She also spoke to the carers of people with dementia in the community. Hanna explains:

*We weren't selling a product, it was more the process ... // ... so I gave (them) a **number of in services** ... // ... we did a training session for **Emergency Department staff and registrars** and that as well, the consultants there. So they were really positive in the whole ... // ... also training **Aged Care Acute Care staff** ... // ... In the **hospital and community care staff** and any service-providers to say that the project was happening, because they might know of people and want to make referral and those sorts of things ... // ... so in-service for the **nursing staff then, invited facilities** if they wanted to be part of the project. We then talked to **GPs** who visited that facility, so we did a couple of talks to GPs at different facilities in that area. We just talked about the project, and that was pretty well received. We only had about seven or eight GPs but they were probably the ones that visit numerous facilities. So they, were aware and said ‘Yes that's fine’ ... // ... So there was the **training to the nursing homes** via in-service. We had **GPs, relatives** meetings, go and talk to relatives' meetings, that's still an ongoing role as are the **RNs' in-services** and things (RN 25: Hanna: CNC).*

The major content of the education sessions were consent, substitute decision-making, and the *Guardianship Act* in relation to different treatments. It was also necessary for the CNC to talk about the prognosis of dementia in order to help the older people and families become fully informed before they made decisions, as they seemed to be ill-informed and to have unreasonable expectations about recovering from dementia.

#### **Narrative 14: In-service education about ACP and ACD enlightened nursing staff**

ACP was not an easy concept to accept for the nursing staff, as it endorsed an individual's right to refuse treatment, which contrasted with nurses' beliefs that they were trained to provide care to the person. Nursing staff including Assistants in Nursing (AIN) in the facility felt uncomfortable and uneasy when an older person was not sent to hospital after an acute illness or when an older person was not offered an artificial feeding regime because the family had decided against it. In-service education played an important role in helping these nursing staff understand about the older persons' and families' right to refuse certain medical procedures at the end of life, as the following, mentioned by Wilma indicates:

*One of the things I found was that often **made staff very uncomfortable** ... because they just felt that we were ignoring the person (by not feeding or not sending the resident to the hospital). And we have a couple of times, especially with residents that had been here a long time and back in the early days most of our residents stayed for a long, long time, and staff got very agitated because they felt that **we weren't actually doing anything for this person** because the family said they didn't want to actively treat the person any longer, for us to treat the person. So, when Hanna presented the topic of Advance Care Plans of Care, I thought that would be really good. When she came and gave the education here I thought it would be really good if we had it in writing and then the staff could see that this wasn't just something somebody had decided to do, you know, it had been talked through as a family, and that **we weren't just neglecting the person**. And it did, it worked very well (RN 7: Wilma: DON 2).*

It was important to commence in-service sessions in a non-threatening manner. The CNC noted that older persons and families who attended in-service sessions felt offended and became emotional when they associated the topic of death and dying with their loved ones. She also had to assure them that ACP was not about abandoning their loved ones in the dying process and to death but about providing them the required services and making the services available in the facility at the end of life.

The training sessions provided by the CNC were well received in that people learnt what ACD was, and what an Enduring Guardian (EG) was. More importantly, people became aware of the need to document their wishes while they were still capable, and started thinking of documenting ACDs. Carla said:

*It was an RN coming from Prix Hospital who gave some education and **started us thinking about doing this (ACD)*** (RN 3: Carla).

#### 4.2.6 Multidisciplinary consultation

Another sub-element that the CNC and the nursing staff needed to work with in the ACP process was ‘multidisciplinary consultation’. It was essential that the multidisciplinary team participated in the ACP process and provided residents with appropriate services in the RACFs. This finding emerged as a theme in the following Narrative.

##### **Narrative 15: They would have had to go to hospital if there was no multidisciplinary team**

The consultations to the multidisciplinary team were mostly made by the CNC and the nursing home staff to GPs, the Palliative Care team, Post Acute Care Service (PACS) team, other CNCs, neurologist, psychologist, psycho-geriatrician, and geriatrician. Hanna explains:

*So the **psycho-geriatric team** might be seeing them (the residents if there was an psychiatric issue). I have only had about three or four that (nurses) have actually said ‘I think they (the residents) need to see the psycho geriatrician first’. It’s been surprising, I thought there would be heaps more. And a few have seen **geriatricians**, have set up meetings with the geriatrician to come to talk with the family as well, after I have met with them (the residents) a couple of times. Some of them are on **Pall (palliative) care or Post Acute Care** as the need arises sort of thing, sort of putting in some extra medical back up* (RN 25: Hanna: CNC).

The key person with whom the CNC and the nursing home staff needed to work well was the GP, because of the GP’s relationship with the older person and the family in the local area. The CNC kept the GPs informed by visiting them or writing them a letter to invite

them in ACP process and to inform them about how it was progressing and what was expected of them. As Hanna said:

*I ring the family, I ring the GP to see if it is all right with the GP (to do ACP) ... // ... Well **they (GPs)'re a core**, they're involved with this patient probably on a weekly or fortnightly basis, seeing the patients, seeing the family. They know all that chronological stuff if they've lived locally. So, just sus [sic] them out because if you are going to go into any planned treatment process, **if the GP is not on board, forget it**, you are wasting your efforts if the GP is not positive about the concept ... // ... Some of them (GPs) I just write a letter to because I know they agree because the patient has sort of said 'Oh look my GP knows what I am doing and he thinks it's a really good idea, he's really keen and interested to hear' sort of thing. So I might write them a letter or go and see them in person. Sometimes if I am close by it is just as easy to pop in on the way back from a visit and explain (RN 25: Hanna: CNC).*

It was necessary for the CNC to have multidisciplinary team input, as she needed some opinions from specialists on where the older person was at with the prognosis and where the person was going in terms of medical problems they presented. This consultation was important, as the CNC believed that it was her role in the ACP that people were fully and accurately informed before they made any decisions for the future. If it was about a matter in which the CNC was not specialised or qualified, she consulted with the personnel who could give her advice. Hanna said:

*I mean I don't have all the information so sometimes I've got to go and **bring the consultant or get some advice or get some information on medication or treatment approaches or ...** so it might mean **talking to the Clinical Nurse Consultant** in that area or, they might say 'Look ring the consultant he will be fine to talk to you' you know if they think this is a really good idea but just haven't got around to getting organised yet (RN 25: Hanna: CNC).*

The consultation to the palliative care team was essential, as one of the most common wishes of older people and families was being free from pain and other uncomfortable symptoms at the end of life. The Palliative Care team from the hospital monitored and reviewed symptom management of residents and the coping process of families. Mia reported:

*Usually the team of **hospital Palliative Care Team**, they talk to the family and then they talk to the DON, then they talk to us (nursing staff in the facility) ... // ... This Palliative Care Team from the hospital, they have to be notified if that medication is responding to the resident so they come and review. They always ring and see, you know, if they (are) responsive with that analgesia or whatever and they just follow it up. They are very good too. If we are concerned we ring them too (RN 2: Mia).*



Post Acute Care Service (PACS) team was also important to keep the residents' or families' wishes of no-hospitalisation. The team worked as a 'mobile hospital' so the residents did not have to go to hospital when they had an acute medical problem. Donna emphasised that the residents might have to go to hospital:

***If they haven't got post acute care service they (residents) might have to go to hospital ... // ... And the hospital has got this PACS team, Post Acute Care Service Team people, where if she has a high temperature, straight away we know it is actually chest infection, that's more likely, if not it's UTI right, so what we do is we just ring up the PACS Team, they come with the Registrar, straight away insert the antibiotic and then she doesn't have the trauma of having to go to the hospital*** (RN 4: Donna).

It was important to work with other health professionals in a multidisciplinary team and usually it worked well. However, the CNC was faced with a difficulty if a specialist opposed to the concept of ACP and refused to work within the multidisciplinary team. Essentially, they do not want to hand over their patient to palliative care, as the following comment shows:

***So if there is a neurologist here or other physicians, kind of catch up, touch base with them. That doesn't always work, sometimes some consultants don't want to hand over their patients to palliative care. I think that is a problem far beyond the realms of this project alone*** (RN 25: Hanna: CNC).

The participation from after-hours doctors in following the written wishes of the older person and the family in the most deserted timeframe at night and/or on weekends was also crucial in the ACP process. Hanna explains how it helps after hours:

***So the plan of treatment has suddenly taken another twist, another beneficial thing is that the after-hours locums can then come and see the Plan of Treatment that has been done with the GP and it is there, and the nursing home staff are saying 'Look they (the resident and the family) have done all this with the GP, they don't really want, they don't need to go to hospital, you haven't got to send them off, we can get pall (palliative) care here tomorrow, can you just write them up for ... you know, or something for their pain or fever or some antibiotics but we will actually follow this up tomorrow, we haven't got to send them to hospital. They didn't want, they don't need all that stuff, or something or the other. So after hours, it is probably helping after-hours doctors too, even though it is a new concept and we haven't been to talk to after-hours services*** (RN 25: Hanna: CNC).

### 4.2.7 Communication

The ACDs documented after discussion and the outcomes of case conferences were needed to be communicated to the staff. There were a number of ways to communicate between the nursing staff, and between the nursing home and the hospital staff in order to keep the documented wishes respected. Communications were made verbally in hand-overs and written notes in nursing progress notes and transfer notes to the hospital. If a resident had ACDs or a POT, the file was marked with a sticker in a distinctive colour and the ACDs or POT were kept in a prominent place in the file. Heather explains the communication system as follows:

*... it has to be discussed what they really want and whether we feel that we can provide it and, then it's just document it in their **progress notes** and, you know, it's, highlighted on the front page that they have got a **Care Plan, a Plan of Treatment** so that it goes to hospital with them if that occasion arises ... // ... Once it is documented we make sure the staff know and we **put a red dot on the front sheet and we put a copy of the Advance Care Directive behind the front sheet** so that if they have to go to hospital for whatever reason or we have to call an emergency doctor in, we can show them what the Advance Care Directive is or we can send a copy to hospital ... // ... during the **handover** probably initially ... and when it is also written on the front page of the **Care Plan** now. It wasn't originally but now it's actually written on the front page of the Care Plan and the nurses are supposed to read that but they probably don't. So it is actually written there that they do or don't have an Advance Care Plan ... // ... We **document the case conference and we document the care plan and we document the progress notes**. There are 3 places and then **on the handover sheets** we always tell them, you know, this resident is for palliative care (RN 5: Heather).*

#### Narrative 16: We need to do better in communication

For Hanna, ACP was more than simply ticking the box off for 'Not-For-Resuscitation (NFR)', and she would like to have a lot more information to communicate with the family in ACP. It was important for her to identify how the resident has been, what has been discussed with the family in the hospital setting, why the resident was referred to her, how the family was coping with the current episode of illness, and what the expectation was. However, when a resident was referred to the CNC she was often not given much information about the resident and the family. Hanna was asked to go and see them because they might have mentioned 'NFR' in the hospital. The written communication by the referring staff who was often brief and Hanna would have to find the information in written notes in hospital files. She argued for improved communication so that she did not have to dig for it:

***They (the hospital staff) don't often tell**, they might say look we have had a discussion not for resus (resuscitation). I tend to get the hospital file before I go out because the chances are, **what they have told me is not what the family want to know when I get out there**. 'Oh the doctor in hospital said this', sometimes you feel like a bit of a done to head, suddenly you have been asked to go and see someone as a follow-up from hospital but you don't know anything about this person. So I read the hospital file before I see them, so then I have got some notes about that to say this was in hospital and that, where it was up to sort of thing, yeah. And likewise if there is a patient that the nursing home is referring, I will try and hunt down to see if they have got a hospital file as well ... //... I probably just get a bit of précis on ... You know I **go through their old notes** or if they have had several admissions, you'll know how long they have been in residential care, what got them in there, (if) they'd had another stroke, or what event it was. So you have got a bit of chronological order of, I guess so that you are a little bit forewarned (RN 25: Hanna: CNC).*

If there was not enough information written by the hospital staff in the resident's file, Hanna needed to communicate verbally with the doctors, nurses, or social workers in the hospital. Her aim is to gain a deeper understanding of the older person's medical history as well as understanding what conversations may have transpired in relation to end-of-life treatment options.

*... (I am ) sort of getting a bit of an idea of how they will function, even though they are unwell, how they were functionally, prior to their admission and stuff and how they pick up and respond, and what discussions have been, had already and so ... **they (hospital staff) don't always write in the sort of discussions or what the outcome of those sort of case conferences and things are**. That's often not documented, I've got to **get that verbally from the consultant or the ward staff, if they recall, or social workers** (RN 25: Hanna: CNC).*

Given that the cooperation from GPs in ACP was essential, Hanna always tried to act in concert with them. Although GPs were not always able to attend every meeting that Hanna had with residents and families, she communicated with the GP via on the phone, in person, and in medical notes in the resident's nursing-home file to ensure the GP clearly understood what had been discussed with the resident and the family with regard to end-of-life care decision-making. As she said:

*I **ring the GP** to see if it is all right with the GP (to start ACP) ... // ... then ... I put either a plan of treatment, if we are starting to develop that, **put it in the GPs' notes** and they can either countersign it or change it or say this is crap, or ring me up. That's never happened. If I haven't had a chance to chat to the GP, if I just got **a letter** you know, your patient was referred, here's the plan of treatment, don't take offence sort of thing, **I am not trying to do you out of a job or anything**. So after you have written a couple*

*of times in the progress notes you might write where they are up to and note that there has been a decision about not for resus (resuscitation) (RN 25: Hanna: CNC).*

Communication between the staff once ACDs were documented was important. However, some were concerned about the possibility that not all wishes expressed by competent residents were heard and followed by nurses in a formal way of documenting it, because of a communication breakdown in the process. When a resident's expressed wish was not communicated but blocked by a staff member, it had an implication in the ACP process. As the following RN notes, sometimes there are bits of communication missing.

*So ... extreme wishes, you know, someone who is able to say what they thought quite clearly can easily be put down and then, it can fall through the loop, not being followed up. So it's only if you have heard because **we don't read the notes every day**. I think **there are bits missing in the loop**, because I think people might have expressed something but it's not really acted on. And (if) it is not acted on to get something formalised, something could happen and we are not doing what they wanted (RN 3: Carla).*

The following example supported the above nursing staff's concern. Flo is a 97-year-old lady who just moved into the Christ Heaven RACF because she could not look after herself any more. Her MMSE was 24/30 on admission. She was a short and small-framed woman who walked slowly from the dining area to her room with a walking frame, who enjoyed food in the facility, who wanted to help other residents and nursing staff in the facility as much as she could, and who would like to keep herself in a quiet spot in the facility. She was independent of ADLs and especially liked to dress herself. The following entry was made in the nursing progress note by a nursing staff.

*The resident was attended for dressing. She said that "I don't want to be a burden to anyone. I would rather be dead." She was given support.*

There was no evidence to say that Flo's comment was investigated further and what support was given to Flo.

#### 4.2.8 Law and ethics

Another sub-element that nurses needed to work with was the legal and ethical implications of ACP. The RNs expressed concerns about whether the ACD was legal. Some were also worried about the possibility of litigation if they followed or did not follow

the written ACDs. It was believed that legislation of ACP and written ACDs would improve the current practice of ACP. As Hanna said, people would want it to be legally binding.

*I think a lot of people would feel **a lot happier** if it, there was some case that said ‘Yes **it is legally binding**’ and I think that’s, even though it is written into policy that it is legally binding, I don’t know that there is the evidence for that yet (RN 25: Hanna).*

Given that there was no legislation for ACP and ACDs in NSW at the time of the data-collection period, and that the concerns that the nurses experienced derived from the lack of knowledge of the law with regard to ACP, it was important for the CNC and the other RNs to know the legal position of ACP – where it was sitting and how it should be practised in the NSW legal system in order to work within the legally sound boundary. The nursing staff’s concerns and perceptions about legal and ethical aspects of ACP are reflected in the following narrative.

**Narrative 17: We don’t know much about the legal side of ACP but we are not worried**

Some RNs were not aware of the legal side of ACP and some were concerned that they might be sued.

*But there is always going to be a legal eagle out there that wants to make something of it. Don’t you think? But ... **I don’t know** where they are up to with Advanced Care Directives. I don’t know what their State Legislature or the Commonwealth Legislature is at the moment, I am sorry, **I am not aware** (RN 24: Suzie: DON 3).*

***You are terrified of being sued**, you are scared of litigation ... if they say, where they make their wishes known, like ‘No please do not send (to hospital) ...’ as in the case of say Kyma, as an example, then we, we really take that ... I mean you have to take it seriously, **it is legally binding**, you know ... // ... Like maybe people would be scared not to because then, Kyma could say ‘Well here’s my wishes, why didn’t you do this?’ ‘I didn’t want her sent to hospital, I didn’t want this sort of intervention.’ So yes, it would be taken more seriously, definitely. And yes we adhere to that definitely. You know there is no, we don’t coerce people, we don’t try and change people’s minds, of course we don’t. We just, we want their directives, their own directives and we ask them to put that in writing, yes, even if it is a letter ... // ... I don’t think any Advanced Care Directive has ever been challenged in courts yet, in Australia (RN 26: Katrina).*

One strategy that nurses has taken to support their nursing intervention in relation to ACDs was that they always asked the families to repeat the directives if what was written was what the families wanted them to do when the older person was having an episode of deterioration or when the situation that the family described in ACDs/POT has occurred. Katrina explains her strategy as follows:

*... every time there is a change in condition, well I always contact them all the time, **even if things written**, yes, yes I say 'Look this is where we are at, this is the, are you still happy about what you've decided'. You know **I always back it up** because you know, sometimes people they might change their mind at the last minute, you know. So I just like to make sure that that's still what they want to do (RN 26: Katrina).*

Krys emphasised 'a joint effort and communication with families' as her way of minimising her fear of being sued.

*No, no. I think because it is all ... it is a sort of **a joint effort**. Everybody is comfortable with it (ACD/POT) before anything is done, you don't do it if people aren't comfortable with it. And ... if they are then go ahead but if not, then you can't, so you don't. **So with everybody in agreement there's very, very little chance with any legal repercussions.** ... // ... I mean it is still in, even in, in every case anyway the family is still given the last choice. You have to do that, just because **there is an Advance Care Directive there, doesn't mean you don't talk to the families about it each time** (RN 23: Krys).*

Interestingly, for some RNs legislation of ACP did not concern them as much. Rosa thought that ACP might not be legally binding at this stage but was an act of humanism. Wilma did not believe that respecting the written wishes of residents or families was unlawful nursing practice.

*With legislation ... (thinking) ... Easier or better for us to talk to people, no **I don't think it (legislation) would matter**, because to me it is a human, **the humane thing to do** if you've got people that are undecided or, or have unrealistic expectations. I mean it is in the Aged Care Standards, emotional support, you know, it is not just about wellness, it is also about managing illness (RN 10: Rosa: DON 1).*

*Well ... **the piece of paper might not be legal but respecting other people's wishes is.** ... I mean ... We've got ... I think we should be. Just the fact that there is no law that says it has to happen doesn't mean that we don't. **It doesn't worry me about having legislation.** No, no. I mean if I go to the doctor and he says, you really need to be taking this tablet and I say no I don't want to, there is no law that says I have to. It is the same thing, I mean, I think, you know, this person says, I don't want to have a tube, they have got just as much right. There is no law about it (RN 7: Wilma: DON 2).*

Hanna spelled out what the nurses needed to be aware of to practise ACP within the guidelines written by the Department of Health in NSW, apart from the legislation debate on ACP. She pointed that nurses should know the documentation criteria, which were capacity, specificity, currency, and witness. It was important for nurses to work within the guidelines satisfying those criteria and knowing what limits were imposed on them, and what they could or could not do. If there still was a problem or conflict of interest between the people involved, then help would be sought through the Guardianship Tribunal.

*If a patient does an Advanced Care Directive and all right, say they come into hospital and they're seen, they're incompetent now but we have got **no reason to question they were incompetent when it was written**. Yes it is specific enough, it meets the **current circumstances**, it meets all the **documentation criteria**, it seems to refer to the situation that's of hand, it is **specific** enough to say what is wanted and what's not. A doctor should be able to follow that in good faith. It is just getting an approach, **working within the law, knowing what the limits are, what you can and can't do and continuing that discussion through in accordance with what you understand the patient's wishes would be, to your best ability**. If you have got a concern about it, that's why I guess I like the **Guardianship Act** because if there is a concern about that and it is minor or major treatment, then we need to go to the **Guardianship Tribunal** (RN 25: Hanna).*

The CNC made herself understood about where she stood on the legal side of ACP and set up the legal boundaries for her to practise in a legal manner. What was also important for her in the implementation of ACP was whether it was ethical where there were uncertainties in the prognosis of an older person and in life. At times she was in doubt about whether it was ethical when ACP was required to develop care plans for the time that the person loses capability. She asked herself questions to justify her practice of ACP in an ethical manner.

*I think all that **ethical stuff too**. There are so many ifs and whats and maybes and perhaps, but it is not clear and it will only become clear once we have seen more directives come into acute care or residential care and go 'Okay this, they are in that clinical picture now, it is irreversible, this is what they want, this is how it applies, this is how we will treat' ... // ... (I haven't got) any qualifications or any claim at all on ethics but it does make you try and think. Not that I know a lot about ethics but just to **try and work in an ethical manner**, which I think means looking at autonomy, beneficence, non-maleficence and you know, sort of scarcity of resources sort of thing. I try not to think about resources too much but good look at what resources are at hand that we can utilise. I'm ... **trying to do the good thing, looking at trying to take on board people's wishes**.*

*Maybe the symptoms don't go away, so it is a problem if we can't express them, so we have got an obligation to enhance positive things in people's lives. So **if that is beneficent, I don't think that's a bad thing.** It means we are sort of taking care of people and providing a good model for providing care for people ... // ... I guess you sort of like to feel like you do the right thing, so you have always got to be on the look-out for what would be wrong and in whose terms is it wrong?... (RN 25: Hanna: CNC).*

#### 4.2.9 Timing of initiation

It was revealed that discussion with everyone involved in the care of the older person about end-of-life care treatment options was critical in the ACP process. The question of when the discussion should be initiated was another sub-element in the ACP process that nurses needed to work through. It was identified by the participants that various timeframes were suggested as the best time to initiate the end-of-life discussion. For example, Laura, who was the Enduring Guardian of Mary had not been offered an opportunity to discuss ACDs while Mary, was in the hospital for aspiration pneumonia. She thought that it would have been easier if she had discussed Mary's treatments and consequences of the treatment while Mary was in the hospital. As she said:

*It was Mary's GP who mentioned it (ACDs in the nursing home). Then Hanna came out. But when Mary was in hospital, no. I think, **it would have been easier in the hospital** ... I wished I had gone over to the hospital when Mary got sick with pneumonia initially. Then I could talk to the doctors and what the doctors told my sister. She told us what was said and they warned us that she (Mary) may not survive but the implications of that we didn't discuss them (FM 19: Laura).*

The data revealed that there were conflicting opinions between nurses on the best time to initiate the discussion. In the current practice of ACP, the residents and families were invited to initiate ACP and offered an opportunity to discuss ACDs when the residents' health deteriorated. It was not until the resident became very frail, non-responsive, with no food intake, recurrent hospitalisation, and very unwell that the initiation of ACP and the discussion of ACDs took place. This approach was projected in the following narrative.

#### Narrative 18: We waited for deterioration

It was assumed by the RNs that the residents or families would not want to discuss treatments that they would or would not want at the end of life when they believed



themselves that they were doing well despite presenting multiple medical problems. The prevalent culture was evident in that people would not want to talk or think about dying and death unless they had a closer encounter to it. So both family members and staff waited for deterioration to occur in the older person's condition before they started discussing end-of-life care or treatment. As Rosa and Krys said:

*I mean at the moment there's nobody that we feel that has got a slow decline. If they are happy, if the residents are happy and interacting well with recreation, the last thing I would probably want to do is bring them in and start saying you know, 'How about the future?' ... // ... it is then very difficult, I'd feel uncomfortable saying to relative in the very beginning ... let's talk about death. ... when they **come in unwell**, that's the time to discuss the issue (RN 10: Rosa: DON 1).*

*I don't know, I have this thought ... If I was bringing my mother into a nursing home, I don't want somebody asking me on admission 'Oh have you thought about funeral arrangements?' It sounds like 'Oh okay, so she is going to die'. So it probably is better if you can, I don't know how you could do it though. It is when someone is well, but how do you initiate that (ACD)? So it usually does come from **a deterioration** first because **when someone is well**, you aren't thinking about it and **I don't know if you really want them to think about it** then because they are happy, you know, so. I think **when people's condition deteriorates**, then you do need to talk about it so that the family understands it ... // ... I think people are more prepared to listen when the time comes. I don't think, when someone is really well they would be like 'What are you talking about, he's fine' and they still see a really well person so I think **there needs to be some element of deterioration for them to actually come along that track, otherwise they don't want to go down there.** ... // ... I wouldn't want to talk about it any earlier than we do and **it's not appropriate for everybody because some people just can't accept it.** So if you try and push the issue on to people who are not going to accept it, you are causing more trauma, so you are better off leaving that one alone, unless you sort of get a feeling that maybe they might come along and start thinking about it. But it isn't suit... some people just can't deal with it so I wouldn't do that (RN 23: Krys).*

#### Narrative 19: Then it was too late

On the other hand, some criticised that the discussion was often left too late if it was postponed until deterioration. Wilma provided an example of the consequence of the absence of an ACD or POT discussion early enough. She said:

*We had one case, Marie, who had been here for I think nearly 13 years, a long, long time (ago). And she had a son and a daughter. The daughter was very understanding of her mother's condition and in the end her mother got gangrene in her foot and she was dying and the daughter made it very clear that she didn't want ... somebody in the hospital spoke to the son, spoke to them both and said, oh we can amputate the leg, but she was basically dying. And the son became very confused and he wanted to do*

*everything for his mother and he wanted her to have the operation and the daughter didn't and there was a conflict there. And we had started to talk to them about doing an Advance Care Directive but it wasn't going to work because there was going to be too much conflict. She died about a week later ... but it wouldn't have worked to do a Plan of Care. It would have just made them fight I think. **It was too late.** ... And **that is the bad part I think about not getting in early enough** (RN 7: Wilma).*

Some believed that the discussion should occur on admission.

*But taking into account most of our residents are not that alert, it's their families that have been doing it (ACDs) and I think **they leave it too late.** It is sort of usually when mum or dad is really **very frail, non-communicative.** So I think **they leave it too late.** And that is why I think it should be discussed. When they come in if they have got a dementia, on admission if I am doing the admission and I feel **it's the right thing to do on admission,** I really feel, we should be able to discuss this with them. Depends, if they are very stressed it may not be the right time to do it. But you might re-approach them a bit later or they might say something again. It needs to be done **not at the last month.** It needs to be done before you get to that stage and therefore I think it would make that passage for everybody, family and the dying easier (RN 5: Heather).*

The RN Rita thought that it was even too late for discussion if the residents were already in the facility. She thought that it should be done while the older person was in the community being able to speak for her/himself. She thought:

*It is **difficult if they are already here,** I think it would be much easier **if they were out there and healthy** and it was part of the routine when you signed your Will or something. I mean it would be much easier, if it was ... if you didn't wait to **quite so late in life** (RN 6: Rita).*

Katrina agreed with Rita that ACDs should be written before the older person admits into a facility and before the dementia steals the person's capacity.

*If a person came in here and they were mildly demented, they would still I think be legally able to, if it was in the early stages of dementia, they would legally be able to sign an Advanced Care Directive and, on admission, I would ask them if they knew about it and were they interested in following it up. But we very rarely get people here in the early stages of dementia. **It is too late actually for them now to put one in because of the level of dementia that they have when they come here. It should be before they get here.** Oh well, before, from the time people know, you know, maybe early adulthood even. I mean for here maybe it should be, **it should be explained to people on admission** or as soon as actually they contact the nursing home. I think I would much **prefer it to be done before they came here** (RN 26: Katrina).*

**Narrative 20: We don't know the best time to do it. It may depend on the person.**

Suzie, who was one of the DONs interviewed, explained that she did not discuss ACDs in depth at the time of initial interview with the family members, as they were experiencing emotional rollercoaster due to the nursing-home placement. She would only mention it for them to start thinking and the handbook written within the organisation would be given for information about ACDs.

*We treat it (dementia) as a terminal illness, so we start to talk about Advanced Care Directives and people's wishes **from the point of interview** (for nursing home admission), when they come for their initial appointment. At initial interview I do not discuss it (ACD) because it was hard enough getting funeral arrangements out of somebody at that time. We **just mention in initial interview about Advanced Care Directives**. I ask the families to think about it and I explain about dementia being a terminal illness and that they are not going to get better and that it is easier for them to make a decision now, instead of going through the emotional rollercoaster of when it needs to be made. It is the same with funeral arrangements and everything. Yes, we've got it in the **handbook** also that we give to residents, to their relatives to, **to get them thinking**. I just ask them, I just say to them 'Did your mother or father ever express wishes of what they would like to do at end stage, when they were dying?' 'Do you know of any wishes that they would have liked to have happening?' 'Have you or your brother or your sister or has anybody spoken about what you would like for this person at end stage?' (RN 24: Suzie: DON 3).*

Suzie believed that the above approach has been working in her facility, however, she would like to develop a system or a process to follow up how the residents and families cope with nursing-home placement and how or if they make progress with ACDs.

*It is working okay for our residents at the moment. Probably I would like maybe **six months down the track after admission, I would like if possible to have something in writing from the family**. That's what I would probably be working towards. It is a huge ordeal for a family to put somebody in placement, it really is and the stress of just doing that is enough. So ... maybe **six or eight months down the track after admission, I would like to have as much information as possible**. It is slow but it is something that can't be done overnight. **It's a huge emotional issue** and you can't stand over a person and say 'I need this tomorrow, I must know exactly what you want to do' (RN 24: Suzie: DON 3).*

Wilma was able to talk to a resident and his son about ACDs on admission. However, it was not easy for some families to discuss ACDs on admission, as they were already upset about relocation of their loved ones in the facility, especially when many people did not even know what ACP and ACDs were.

*It's just now that we are trying really hard to get people to start to think about it when they first come in unless they are really upset. Yes I do (talk about ACDs). ... when I do my admission, when they actually come to do the admission they are in tears. They are very upset and so it's not really a good time to raise it (ACDs). I might, I might ask do they have an Advance Care Directive but if they say no, I probably don't take it any further at that point if they are really upset, and that is where it would be nice to have that pamphlet to give to them. But if they say no and they are not really upset, then I would tell them **what it is and ask them if they want to make one**. One is Mr Brenn, I asked his son before he arrived (in the facility). I said, because he has a terminal illness, I asked the son, does your father have clear ideas about his ongoing treatment and his son said, oh yes, he does. And I asked his son does he have an Advance Care Directive and he wasn't sure. He didn't know. So when Mr Brenn came, I asked him did he have an Advance Care Directive and he said, no he didn't. But he agreed with his son that he had very clear ideas about what he did and didn't want to happen, and so I immediately involved Hanna in that case (RN 7: Wilma: DON 2).*

Wilma summarised when the discussion for ACD has occurred in the past and in the current nursing practice in her facility. She proposed a suggestion for the future practice of ACP.

*What I would like to do and I have been working on but it has been a bit slow, is I am putting together **a pamphlet** that I can give to the families so that if it is not appropriate to talk to them I can give them the pamphlet and hopefully we can then **talk about it later**. **Back in the early days, it would always be after the person had deteriorated** and it was normally when the family would be called in because the person had deteriorated and they would normally be upset. Now I think we **try very hard to get involved with the family before that happens. Before the resident deteriorates** and we have done that very successfully with a few residents who have since died and the families have been quite pleased with that. ... // ... Well I think you should start people thinking about as soon as they arrive. I mean, I think before, **I think before they get here**. It should be something that is discussed, it should be something that people are aware of and are thinking of. But I think if they haven't started to do it, I think when they come here, you know, **they should be thinking about it when they are not distressed** (RN 7: Wilma: DON 2).*

It was clear that the initiation of discussion required a sensible and individualised approach in the ACP process. The RN Rosa mentioned how and when they approached residents and families for ACP.

*It **depends on the resident** and ... It depends on whether you feel the resident is ready to talk about it. Whether the family will be offended if you start saying 'Well look you know, do you want him to go to hospital or did you want to sit down and have a conference'. Probably if we had more frequent conferences it might be better for that, but time is the problem (RN 10: Rosa: DON 2).*

The nursing staff had to be very conscious of how and when to initiate the discussion of ACP. Given that the families had difficulty in accepting the fact that their loved one would die, it was not an easy task for nursing staff to commence a conversation about end-of-life care wishes. They had to build up a good relationship with them first and to use their intuition and experience in doing so. Heather said:

*Well you have the question on the form about dying, for burial or cremation and that is usually a good way in because you know you can make a bit of a joke about it and they, you just say, have you given any thought about at the end what sort of care you would like? Well that is what I said earlier, this is when I come around and I just ask them (residents, families) have they thought about it (ACDs) because you get the thing. ... I have asked a couple (if they have one) to be honest, I did. But **they didn't know what I was talking about** so then I was able to go into it. It is instinct with some people. I am sorry, you can't just say yes, you do it with everybody because you can't. It's the same as asking this question, like are you for burial or cremation, you can't always ask them that either on admission. **You have got to be really careful, because they get really offended.** You just, I don't know, it's just something that you do carefully. You can upset people very easily. You have got to get to know them first and then you might be able to broach that (RN 5: Heather).*

Theo's father passed away seven years ago. His sister Tia was diagnosed with Multiple Sclerosis (MS) 17 years ago and she was at end stage. Tia occasionally gazed at something on the ceiling and opened her eyes wide, but other than that she did not respond to any stimulation at all. Theo was asked if it would have been easier for his family if the prognosis of MS, had been explained and they had discussed end-stage care plans for Tia while she was still able to understand and express herself. He suggested an individualised approach with regard to the timing of initiation of the end-of-life care discussion, as it might cause guilt by pre-empting all the possibilities. Theo said:

*I think that is a very important discussion to have, it is a practical discussion more than anything else. But in the case of my sister, at that time, I am just imagining now, if I put myself back some years to 1995, have that discussion, I would have felt like, **we are pre-empting it, we are giving up on her**, you know, it would be just **too much, too heart-breaking**. I guess it just depends where you are in life, whether you have faced death before, whether you have experienced it before (FM 14: Theo).*

Whilst the opinions on best timing for ACD discussion were varied, there was a consensus that it would be ideal if the ACD discussion occurred before the older people lose the capacity to make decisions, whether it would be in the hospital, community or RACF. If it did not happen, then the next opportunity would be in the initial interview for nursing-home placement to touch on the concept of ACP and to prompt thinking about ACDs. Handbooks or pamphlets could be used at that stage. It was agreed that deterioration of

health or the last-month approach were not endorsed for the practice of ACP. Most importantly, an individual approach for initiation of ACD discussion was recommended.

#### 4.2.10 Obstacles/difficulties

The last sub-element in throughputs that nurses had to work with in ACP process was the ‘obstacles’. Considering that ACP was a new concept and what Hanna was trying to implement was a new approach for residents, families, and nurses in RACFs, it was not surprising that Hanna and those who embraced the concept well had not only to work with the sub-elements mentioned above but also to work out the difficulties presented to them.

#### Narrative 21: ACP/ACDs/POT as taboo subjects

The most frequent and serious difficulty that they needed to work with was that death, dying, and end-of-life care were taboo subject for discussion. In fact, it was a taboo for almost everyone, including the older people, families, the nurses and the GP as well. Hanna explains the response from older people:

*It is part of the process that we recommend people (to) think about who their decision-maker is, (It) is the highest thing. Then there's [sic] people who haven't done any of that thinking. And let's face it that is the majority of people, it is human nature, **they don't want to know about it, they don't want to talk about it. Everyone is in denial.** ... // ... because they are not actively dying, they're not gurgling and gasping on their last breath, they **don't want to talk about it, because it's taboo** or whatever, you don't ever get passed that to know why or is it, you know, is it offensive to talk about it, is it taboo? (RN 25: Hanna: CNC).*

Hanna received similar response from the family members.

*So **it was families... a lot of them weren't keen**, like it did need the nursing homes to sort of push it a little bit and I guess because it was new, they were testing the water a bit themselves too. ... // ... Because you sort of think 'maybe it's not right, are we sort of... you know, **jeopardising or jinxing people** by it (talking about ACDs). ... // ... That's where I had about 30 people came along, and **some people, they didn't want to talk about it** (RN 25: Hanna: CNC).*

Hanna realised that some nurses refused to discuss end-of-life care issues.

*Some staff have got very **closed minds** where they don't want to think about that (end-of-life care issues), they just say 'It is **not my job**' (to discuss dying and death with*

*residents) and you make no progress there so just give it up as a bad joke (laugh). Like 'No, I'm not doing it (talking about dying and death). No, no, I don't have to, I don't ...' So that's people's mind set and you can't get away from that, so be it (RN 25: Hanna: CNC).*

It was a common misunderstanding and misperception that ACD was the same as euthanasia and was to prevent older residents from coming to the hospital. Whilst there were people who showed interest in ACP and accepted it, Hanna was challenged with negative attitudes from some people who perceived ACP as 'euthanasia'.

*The other difficulty is **people's perception, it's euthanasia** and it is just completely not. It is just people's perception if you are talking about death and you are trying to plan a good one, that **it's got to be euthanasia but it's not**. No it is an act to actually, and it is sort of reminding people of our obligation to promote health and wellbeing. It is sort of the higher order of things (RN 25: Hanna: CNC).*

Another difficulty that all parties experienced and were responsible for, and Hanna had to work with, was lack of commitment to the implementation of ACP in RACFs. This difficulty is reflected in the following Narrative.

#### **Narrative 22: Lack of commitment by managers, RNs, and GPs**

Katrina said:

*I mean a lot is expected of a DON, by the time you have to deal with all the petty in-fighting of the staff, the rostering, the pay sheets, all that junk, the last thing probably that you are going to be thinking about in all honesty, is Advanced Care Directives. You may want to, you may want to do all this stuff but really **it is so hard to do it**, you know (RN 26: Katrina).*

Carla talked about lack of commitment from the RNs:

*... **not all the RNs will take that (badger, messenger) role**. Some, some are just if it's written, it's written, but if it's not, it's not. And I don't know, I don't know, if they may be as aware because of the times they work of Hanna's role (RN 3: Carla).*

Lack of commitment from GPs was also noted by Rosa:

*(Drs) wouldn't want (to know about ACDs) and then it would take more (time) but I mean that's all part of the deal, well if you (the doctor) are going to do it that way (not want to know), we do involve other people (another GP). Some people (GPs) are just difficult* (RN 10: Rosa: DON 2).

It was often considered that other issues such as the Resident Classification Scale (RCS) review – a funding reimbursement tool – and high staff turnover had detrimental effects on the ACP process. Hanna noted that positive attitude and commitment from managers to nursing staff were requisite and sufficient to successfully implement the ACP process. The managers had to accept their responsibility and to lead the implementation process. The RNs needed to be motivated by accepting their responsibility in ACP and having regular staff members working together were vital to succeed in the implementation of ACP. Hanna explains:

*I think some of the facilities have probably got more **regular staff** where it has been successful. Other ones who've put it in they're, it's all too chaotic and they don't want to think about it, it is another thing to do. So a lot of it is **attitudinal amongst the staff and the management**. I think it has been successful in the facilities, it has been because there is a **commitment by the management and nurses** there, because they want it to work because they, there's a recognition that everything else was madness if we don't do it (chuckling). And they can, the places that don't do it, they continue to be mad places but I think you have a happier group of staff and they're working in a good supported organisation and that's what helps do it (ACP). **If they are too busy doing their RCS reviews, it is just another thing to do. That's not on their agenda.** If they've got, some nursing homes have, one day where they haven't got any RNs on, they are all agency staff. Then it is just not in their scope, it is just not in their head spaces. **I think the elements are certainly that you've got stable staff, good leadership and management in place, and a willingness of the RNs to actually want to get that on board** (RN 25: Hanna: CNC).*

High turnover of the nursing staff in RACFs has exacerbated the difficulty with the lack of commitment from the RNs to ACP, as it emerged in the following Narrative.

### **Narrative 23: High turnover and lack of consistency in attendance**

Hanna said that high turnover affected the lack of commitment from the nursing staff. She said it was:



*... the **changeover in staff all the time at nursing homes**. Sometimes I feel like I am going out presenting something that's completely new to people, I have been doing it for five years. It is just that that day, the staff haven't heard it before, so ... with such high demand for nursing staff, a highly mobile workforce that turn around, some facilities don't retain staff. So it is hard to keep the momentum going. You can have a very passionate group and six weeks later they have all left and you have done all this work with them as a facility and then you **go back and start again** (RN 25: Hanna: CNC).*

High turnover also had a negative effect on the number of nurses who attended education sessions for ACP and who were prepared for their roles in ACP. Lack of consistency in attendance of the RNs in education sessions meant a lack of nurses who were confident in practising ACP. Carla said:

*... maybe they (the RNs) are **not as informed of the Advance Care Directive or Plan**, you know. The family get together and make a plan. So there are different levels of it, so I think at our level, on the coalface **we could have more information about it**, just to be aware and maybe things that we could be giving the relatives to think about too. It is a sensitive thing so some people (RNs) may not feel comfortable to do that (RN 3: Carla).*

It was admitted that the RNs were not prepared for their roles in ACP. They obviously foresaw the emerging roles for the RNs in ACP, however, demonstrated lack of confidence in understanding what ACP/ACD/POT were, how they should practise, and what the consequences were. Carla believed:

*... a lot of the nurses have an expectation or belief that the doctors have that discussion. But the doctors don't always have that discussion, so then, we are at the coal face of the family saying, what is going to happen to mum or dad? And we say, what do the doctors say, what did they say, and they say nothing. So again, I think it is **a role nurses are stepping up to, maybe unprepared**, maybe, am **not sure of how much to say or not to say**. There is all this question. There is **not a lot of clarity**, it makes our job really hard, you know, you don't want to give people false hope, but at the same time you want to reassure them, to spend quality time with their family (RN 3: Carla).*

For Donna and Rita, it did seem difficult to define what ACP was:

*Advance Care Planning is uh ... (long pause) if it applies to the elderly people, it means what will happen to them when the time comes. Yep, and all I know is we, we get the team from, uh .... if they have cancer or whatever, we get the team from the hospital. It's called **Palliative Care Team** and they will try and make the person as comfortable as possible. Advance Directive, we call that (RN 4: Donna).*

***I might be quite wrong, to me an Advance Care Directive is what do you wish, particularly if you have got children that might be involved in the direction of your care. It gives them also an idea as to what you actually did want in the first place*** (RN 6: Rita).

It was suggested that a systematic approach is required to address high turnover and an effective way to deliver education sessions for unprepared nurses in RACFs, as it impeded the outcomes of ACP for residents and families.

#### **Narrative 24: The terms are not familiar and abstract thinking is hard**

Another difficulty experienced by the participants in implementing ACP was that there were many people who have never heard of the terms ACP, ACDs and POT. The residents, their families and nurses did not know exactly what ACP and ACD were and they were not familiar with those terms. It resulted in causing extra anxiety to many and in being misunderstood as euthanasia when introduced by the CNC. What they understood was more close to 'Palliative care in the nursing home' and it started to appeal to some residents and families. The study participants did not mention ACP and ACD but did name it '(future) care plan', 'palliative care', 'discussion', 'statement', or 'care protocol'. Katrina told the researcher about her experience:

***In my experience, I actually had never even heard of an Advanced [sic] Care Directive until a couple of years ago and I didn't know they existed. I had heard of Living Wills but, and I had an experience in an Aged Care facility I worked at about three years ago where someone had a Living Will, where she had stipulated that she did not want to have active resuscitation or she didn't want active cardio-pulmonary resuscitation in the event of her becoming in a vegetated state, from memory I think she had been diagnosed with Pick's disease. And her wishes were respected. She was quite a prominent member of Sydney society. Other than that I had not had any experience and there didn't seem to be a lot of knowledge about Advanced [sic] Care Directives, and I would include myself in that*** (RN 26: Katrina).

One facility involved the CNC only recently for the implementation of ACP. The practice of ACP in the facility in the past was that family members or residents were asked to express their end-of-life care wishes in a 'statement' if they wanted to. Given that the majority of people did not know what ACP and ACD were, it was not surprising that they had difficulty in writing up end-of-life care wishes by themselves with their own words. There were four family members (out of 45 residents) who had made the 'statements' on

behalf of their loved ones. One was an RN who knew what ACD was and what her mother would have wanted. Another family member was an economist who had a solicitor as a brother. The other two family members were known to be teachers.

*... the families seem to **have difficulties in writing up**. It is hard for them because **they have never talked about it**. ... //... Yes, it does (take time), I don't know whether it takes time for them to accept it, whether it takes time for them to actually do it. I think the acceptance is there for some but just **getting around to doing it's the main hurdle**. I just know with a resident that we lost recently, who'd been here since July '97 ... and it was only three weeks before this person passed away that I happened to be in on a weekend and saw his son and just happened to mention it, and he said 'I have been meaning to get around to this for so long, to put something in writing'. And three weeks later this person passed away and I just think it's initially ... **it is actually doing it is difficult, so hard** (RN 24: Suzie: DON 3).*

Hanna as an expert nurse was not surprised and had an explanation for it. She pointed out that the difficulty with ACP for many lay in 'abstract thinking'. It was hard for many people to imagine what it would be like to lose mental capacity and to be unable to say what they would want. Hanna noted that it was almost impossible for many people to put all the possible treatments that they could go for and the consequences of those treatments together and to decide what they would want and would not want without her assistance. Hanna developed the strategies to help people with 'abstract thinking' such as the values clarification form and many other questions to draw out and lay out so that they were able to express their wishes in ACDs or a POT. Hanna said how she helped people with abstract thinking:

*Sometimes they don't, they don't quite get what you are talking about and you've got to be realistic there. The resident just doesn't ... they seem to be capable but it's **all that abstract thinking**. One exercise when I first started here was to try and do my own intolerable statement and it's, you know, you sort of put yourself in the position where you are lying in bed, you are sort of half asleep and you're not really aware and then someone came in and spoke to you. Well you wouldn't know who they were, is that just a noise or are they talking, or do you know that voice. Like how do you ... **it's really hard to put yourself in that position where you're not able to interact. It is difficult for people to picture themselves in a position where they won't be able to say what they want to happen. They just don't get that concept that it only is going to apply when they don't have mental capacity**. You have almost got to be exposed to dementia and how people can't think and have been a sort of a regular carer for someone with dementia ... //... **capacity is a big issue, but that phrasing and intolerable situation is a way of doing that**. Some will have, (be) more able to do it more easily than others, some struggle with it, so that's why **I think that values clarification helps in getting to being...** **That helps us to find what is specific, at what point does this apply**. And ... maybe it is a point of caution I would put in if you were phrasing something, **you want to be specific in terms of intolerable situation**,*

***you'd need to add into that statement 'and this condition is irreversible'. Ah capacity... it is so big, such a big area to enable people to be able to have the conversation. We value autonomy, to lose their ability to think then they are not going to be autonomous and that's what we've got to get our head around. So talking about what's important, talking about values, talking about, getting that narrative, history and milestones and what defines you as a person will help us*** (RN 25: Hanna: CNC).

In summary, the researcher described ten sub-elements that nurses needed to work with and through, in the implementation and process of ACP. The Guardianship Board provided the CNC and the RNs in the facilities with guidelines to practise ACP in the absence of legislation. They used a number of documentation systems to initiate, progress and practise ACP. The RNs at managerial level organised case conferences to initiate the conversations about end-of-life care. Both formal and informal discussions with regard to who the person was, how the person lived, and what the person would want at the end of life were crucial in the ACP process. Information sessions delivered by the CNC educated and empowered all parties involved. It was essential for nurses to work with the multidisciplinary team to respect the older persons' or families' wishes of not being sent to hospital and not being treated against their wishes. The discussions and decisions made, through case conference and discussion, were communicated in various ways. The CNC and the RNs needed to work through/for/within legal and ethical boundaries. Initiation of discussion about end-of-life care preferences was a sensitive matter that required an individualised approach conducted in a timely manner. Although the CNC and the RNs identified the difficulties they encountered, such as seeing ACP as 'taboo', lack of commitment, high turnover in staffing, and abstract thinking, a number of strategies were taken to implement ACP and to help residents and families with end-of-life care decision-making. The researcher now describes the last element of the conceptual framework in the implementation of ACP.

### 4.3 Output

The ACP program was implemented by the CNC as a pilot project in an area in NSW. The data revealed how the ACP program was implemented and the process of ACP disclosed confirmed that the inputs were required to initiate the process. The throughputs that were essential to work with/through in order to attain desired outcomes have been described above. As a result, the outputs of implementation of ACP process were generated and

identified in the outcomes of ACP for residents, families, and the RNs. The data revealed that the ACP process generated positive outcomes for the residents, family members, and the nursing staff in RACFs. The ACP process resulted in documentation of ACD/POT, autonomy for residents and clear directions for nursing staff, Person-centred care (PCC), dying with dignity, change of culture and attitudes about dying and death. The following section describes each of these outcomes.

### **4.3.1 Documentation of ACD/POT**

The most obvious outcome of the ACP process was the documentation of ACDs by the resident themselves or POT by the family members. There were three ACDs and three POT documented with the involvement of the CNC during the data-collection period. Another two POT that the CNC facilitated in previous years were also included for review. Five of the letters written by family members with regard to end-of-life care preferences without using the POT form also produced consistent outcomes.

The participants were asked what the most common decisions made by the residents and families in ACDs/POT were. This question was important to ask to start with, in order to increase the researcher's understanding of what the residents, families, and the RNs experienced during the ACP process. It helped the researcher to explore through prompting more, and in greater depth, why they experienced what they experienced and why they felt the way they felt.

The most fervent wishes expressed by the residents and the families were for 'no hospitalisation', 'not for resuscitation (NFR)', 'the use of palliative care', and 'no tube feeding'. One can only imagine how sad and difficult it would have been to write down 'do not send my mum/dad/wife/husband/sister/aunt to the hospital and do not resuscitate them', in a legally valid form. It was also important to question at this stage whether the residents felt sad and uncomfortable when they documented 'no hospitalisation', and 'no CPR' for themselves. This will be discussed later. The following section describes the most prevalent decisions made in ACDs/POT by the residents and the families through ACP, revealing the images projected through Narratives.

**Narrative 25: ‘No hospitalisation’ and ‘no CPR’ because it doesn’t do good, there is no benefit, no dignity**

‘No hospitalisation’ and ‘NFR’ were the most frequently expressed wishes by the residents and the families, according to the RNs involved in ACP process, as it was believed to do more harm than good, to provide no benefit and to interfere with an older person’s dignity. Krys explained how documented wishes of ‘not to send hospital’ preserved the dignity of older people:

*It is related to specific things like **not sending someone to hospital** every time they get an infection but rather organising that somebody else, a PACS team can come out here or so people can actually **die with dignity** and not have to be thrown backwards and forwards to hospital and things. We would have case conferences with family members where they would discuss, you know ‘No **we don’t want him to go to hospital** if this happens, we would like you to keep him here comfortable’ (RN 23: Krys).*

Heather also said that the most frequently expressed end-of-life care wishes were:

*... mainly it’s **not for resuscitation**, that is the big one that they put in.... //... Mainly if you read them there are all **not for resuscitation** and you know **not to go to hospital**, no major interventions and to be **kept pain-free and comfortable**. But they don’t, most of them **don’t want to go into the hospital** for the long term or surgical interventions, etc. That’s usually the outcome for most of our people here (RN 5: Heather).*

The reason behind the decisions of ‘no hospitalisation’ and ‘NFR’ was because there was no benefit in sending someone who was at the end of life to hospital. It was believed that hospitalisation equated to ‘no dignity’ and keeping the residents in the facility meant that ‘dignity’ was preserved. Katie said:

*What we discussed are ... **not sending them to hospital**, pros and cons and towards the end of her, like they realise now, **she is not going to benefit**, she is not going to get any better, she can’t have physiotherapy and it all goes back to Tia, I think it traumatises them (Tia and her family) going to hospital. I think she (Tia) is more comfortable, stay here than she is going to hospital (RN 13: Katie).*

Suzie also explained:

*We’ve got two others that thought it was a great idea and they don’t want their persons, their relative, mother or father or husband or wife, **they don’t want them to go to a hospital, they don’t want invasive treatment**. They want that person to **die naturally with dignity** and they don’t want them to go through, you know, procedures and operations if they don’t need to, because they know **it’s not going to make a***

**difference to their wellbeing ... //... I mean if somebody falls, yes, and they need emergency treatment, yes, they will be transferred. We have got registered staff on 24 hours a day so if we can monitor and treat the person in-house here, there is a much better outcome for the person and the family and for the staff. Um ... a **hospital admission for a dementia care resident is not, is not the best option, it really is not**** (RN 24: Suzie: DON 3).

The two requisites emerged as necessary in order to satisfy the wishes of ‘no hospitalisation’, and ‘NFR’ if the residents did not want to be sent to hospital and the families did not want their loved ones transferred to hospital. One was that the RNs were able to manage the care required at the end of life in the facility. There were other health-care teams available that joined to provide ‘hospital’-equivalent care in the facility. So the duty of care for the residents and families was secured and fulfilled by the RNs and by the mobile hospital team, such as the PACS team and palliative care team. Donna was proud to say that:

**‘Do not send to the hospital’** because, they don’t even want (to go to hospital), **it’s not for resuscitation** anyway. So that’s the trigger sort of thing, too many times to the hospital. The thing is, what they can do in a hospital **we can do here**. That’s what we tell them and it’s true because the team from the hospital come here and (do) the same thing, give IV antibiotics same thing (RN 4: Donna).

Suzie was happy with the involvement and services of the multidisciplinary team:

So with the services, the **PACS team and palliative care team**, you know, we can do it in-house and it is much more comfortable for everybody concerned. The staff miss the residents if they are gone because they are part of an extended family and they worry about them and they go off to hospital to visit them because they know that they are not going to have the attention that they have here. So it is a much better option (RN 24: Suzie: DON 3).

### Narrative 26: Palliative care and beyond

Another end-of-life care wish frequently mentioned by the residents and the families was ‘palliative care only’. For the participants including the RNs, palliative care meant ‘pain-free and kept comfortable’. Shelly shared her experience:

Lynda, the wife, Eddie’s wife, was here and doctor talked to her and you know ... and we want the best for residents, we just **want them comfortable** and that’s why doctor put him on a patch, **patch for the pain**. That’s it, this is just the, I think this is the best way for that kind of resident you know. And he was **free of pain** and he didn’t suffer too much, you know. And yesterday when I am [sic] just talking to Lynda, Lynda was

*quite happy you know, she just wanted ... Eddie was **free of pain**, that's it, and I think he was, **he didn't get any pain and he was comfortable** and he just passed away. Of course it is hard for the family, you know, children, but the main thing is, he didn't suffer, he just died you know, peace and quiet. Yeah (RN 15: Shelly).*

Providing palliative care meant more than 'free of pain' in end-of-life care. It meant that the person would be taken care of as a whole person and that the person would die with dignity. Krys said:

*So you know pain is a big issue because it causes a lot of other problems as well, so I think dealing with that is the same thing. You deal with all these things together really, you are **dealing with the person as a whole person** and that's everything and so at the end of their life you want the whole person to have a comfortable, dignified end (RN 23: Krys).*

For some family members, it was not clear exactly what palliative care meant and how it would affect the care of their loved ones. Therefore, they needed explanations and education. What Mia experienced was:

*Usually they say for palliative care, I explain about palliative care to them. We say, okay, if you are you know, we explain what is palliative care because **they don't know what is palliative care** ... then we put them in palliative care ... because most of the time the main thing is they are **free of pain** (RN 2: Mia).*

The RNs took pride in being involved in end-of-life care activities and collaborating with the palliative care team in order to respect the wishes for end-of-life care. The palliative care team from the hospital would be in charge of choosing and prescribing medications for pain and discomfort. They also provided the families with counselling for those who were in grief. The RNs in the facility would assess and evaluate whether the pain management regime was working. Krys appreciated the involvement and services of the palliative care team:

*We would have case conferences with family members where they would discuss, you know **'No we don't want him to go to hospital if this happens, we would like you to keep him here comfortable.'** ... //... **They (palliative care team) look at the medication, they talk to the family.** They will keep the person **pain-free**, they usually write up some regular analgesia and some break-through analgesia. They will come and see to make sure that their regime is effective and also not causing too much problem with the bowels, stuff like that. And they also have **support people**, like, **bereavement people** that the family can talk to, and I think once the family speak to the palliative care people, they feel **more comfortable** with allowing it to happen because, you know, they're obviously so concerned about the person **being***



**comfortable and pain-managed** well, etcetera. *So I think it works out very nicely for the family as well. ... //... We do frequent pain audit and things like that* (RN 23: Krys).

Palliative care was often misunderstood as ‘do nothing’. However, it was important to note that palliative care did not always mean that the residents would be left to die without getting any appropriate treatment. It meant that the resident would not be actively treated to prolong life but would be actively treated to provide comfort. Given that the purpose of palliative care in ACP was to promote comfort and well-being until death, the concept of palliative care prevailed and expanded even to sending the person to hospital and to performing an operation if it helped the resident’s situation. Hanna said:

**Some will want to go to hospital, treat what’s reversible, have investigations, have surgery, and realistically for those, you know, if they have a bowel obstruction then they can go and probably have them (operation), that’s the best way to fix the problem despite that they haven’t got any language and aren’t interacting. You know, they are in pain and something is found that is severe enough to cause a lot of distress that a regular dose of morphine isn’t going to fix. They are going to be in pain. So some people, one lady went in with a plan of treatment, had bowel surgery and is still alive. She’s outlived her husband** (RN 25: Hanna: CNC).

#### Narrative 27: ‘No tube feeding’

It was noted that the families demonstrated mixed attitudes about feeding, unlike other end-of-life care issues. The residents and families wanted and documented ‘no hospitalisation’, ‘NFR’, and ‘Palliative care only’. However, when they came across matters related to feeding (oral feeding, Naso-Gastric (NG)/PEG tube feeding, IV feeding), their wishes varied from ‘unable to decide at current’ to ‘no tube feeding’. Some families were sure that they did not want their loved ones fed through any artificial means and documented particularly ‘no tube feeding’. Carla shared her experience:

**She doesn’t want tubes (for food), she wants to be comfortable, no pain, but she doesn’t want to be on a tube for the rest of her life, you know** (RN 3: Carla).

And the family’s refusal for tube feeding became a cause of conflict between the family and the GP when the family’s wish was contrary to the GP’s belief. Wilma said:

*I mean things like pain relief and pain management (are not a problem) but one subject that comes up a lot is the **feeding** and it depends on what the family want. Sometimes*

***the family don't want tubes and it is, I think this was the issue with the doctor because the family didn't want her to have a tube*** (RN 7: Wilma: DON 2).

It was hard for some family members to decide what level of feeding the family wanted for their loved ones at the end of life, given that deprivation of food was associated with causing neglectful death of their loved ones by starvation. Therefore, the decision with regard to feeding had to be left 'blank' or 'open for discussion as necessary'. Hanna explained:

*If it's not consistent that I guess you leave some things blank. Like some families we have talked about CPR and level of treatment but the whole idea of feeding, **they haven't really got their head around**. So you can just walk through that, say well to be determined as the need arises or continue as is and you **don't necessarily refuse anything**, you just leave that blank for all those levels of feeding. So you are going yes, continue with basic feeding but you leave the others blank, well there has been no decision made here about yes or no. Sometimes in those levels of treatment I won't have yes or no, I will just have blank, it means it is sort of open, open for discussion sort of a time, it might have been a bit hard to think abstractly about 'what if this time comes and this, do you want a drip and do you want this and that'. It is a bit hard to draw it all out, especially on someone else's behalf* (RN 25: Hanna: CNC).

The most commonly documented end-of-life wishes in ACDs and POT include 'no hospitalisation', 'not for resuscitation (NFR)', 'the use of palliative care', and 'no tube feeding'. However, it is crucial that these wishes cannot be separated from the context that their wishes were documented and should be followed. For example, Morton did not want 'CPR' under any circumstances, whereas he would accept 'limited level of care', which includes palliative care and antibiotics in case he has a reversible illness. However, he would accept 'palliative care only' if it is an irreversible illness. The intolerable situation described by Morton when his directives should take an effect is unique, elaborative, and specific to him only. He stated that his directives should take an effect when he is incontinent of faeces or when he is unable to recognise his friends and when this situation is irreversible. Interestingly, for Jill, being useful to her family, friends, and community was the most important purpose and intention of her life, which represents integrity of herself. Therefore, it is in vain and inappropriate to try to frame or quantify each ACDs and POT documented representing an individual's wishes without understanding the whole context regarding where, how, and why the wishes came (from).

### 4.3.2 Autonomy for residents and clear directions for nursing staff

Krys, Katrina, and Wilma, who have been working in RACFs for more than 20 years, agreed that the residents and the family members have been taken away from the right to choose how to live and how to die and it was now time to give this back to them. The ACP has ensured that the residents and the families had their control back in their own hands and provided the nurses with an opportunity to identify what the residents and families would want and would not want at the end of life. The RNs were happy to give the residents and families back their right to choose and to follow the directions given to them in ACDs/POT, as the following show.

*I see people, people and their families having more of a choice with what happens to them so that they are not being ... they are not being made to go backwards and forwards to hospital for no real benefit to them. Like you might be prolonging their life but you are not prolonging the quality, you are not improving the quality, just improving the length of time and for some people that is cruel because they, they would probably prefer not to be there and giving them more of a say in what happens to them. Surely it's their right, **they have right to choose how to live**, so they should be allowed to choose not to be kept alive or whatever (RN 23: Krys).*

*... people would be able to say how they wanted their end of years to be handled in case they lost their ... in case they became fairly severely in cognitively impaired, so, so that **the decision would still be with them** even though they would not be aware of what, what was happening at the time, which I think is a really great idea (RN 26: Katrina).*

*We are not telling them this is what is going to happen. **We give them back the control** and everything else about coming into a nursing home, we take control away from them and this gives a big part of it and an important part back to them. And to me that's, that's really good (RN 7: Wilma: DON 2).*

Whilst ACP provided the residents and family members with the right to make decisions, the ACDs and POT documented provided the RNs in the facilities with clear directions about what to do.

#### Narrative 28: It gave us clear direction of what to do

The RNs were happy for themselves, as there was a clear direction for them to follow in providing end-of-life care. Whilst ACDs could not possibly address all kinds of situations

and preferences that a resident mentioned, Heather was affirmative about ACDs documented in that:

*Well it (Advance Care Directive) is **a guide** to what we can do for our residents when they actually get into the stage where we think they may need palliative care or they need to have some interventions for their lifestyle and quality of life. ... //... I think it is being pro-active in life in your treatment* (RN 5: Heather).

Rosa, as a manager, explained her observations:

*They (the nursing staff) are happy, they are happy because in Tom's case we just have his plan (POT) okay, but if there is [sic] medications that might need to be given at the time like with the respiratory problem, there will be a laminated notice in the folder stating **the wishes of the person and what to do**. Contact this, contact the Palliative Care Team, da, da, da, da, da, and medications are in there for that person, he has a chart. So they go 'Oh he's got this, chart out, give the medication' and the person remains comfortable. So I think they (the RNs) are quite **happy** with that* (RN 10: Rosa: DON 1).

Katie, who was the RN on the floor, found repetitive hospitalisations time-consuming and was challenged when she had to make decisions for a resident who did not have directions for end-of-life care. She found that it was easier and clearer with residents who have documented their POT, given that she could follow the directions step by step.

*Well I mean I open the file and think 'Oh great' you know 'Has the seizure, do this, do that, do that' We let the palliative team know what's happened and it is good, I mean it is less for us really. ... //... Yeah, it's paperwork, always paperwork when someone goes to hospital and coming back, it is so much, it is time-consuming, in that way, yes, yes. ... //... Yes I do feel it **easier**, especially like Eva Thompson. How far do you treat them? Well I **know what to do, straightaway**, I just have to open the book and I know what to do. Especially, she (Tia) has had a seizure, I get the, she has the pack, I get that, watch her, if she is febrile we do start her on antibiotics at the moment, um, and we follow that through* (RN 13: Katie).

Krys also agreed that directions and plans written for end-of-life care saved time, as the steps to follow were written in black and white when the decisions made to keep the resident in the facility. She found that the directives written would be particularly useful for those who did not work in the facility regularly and therefore, did not know the resident or family member very well.

*Management aren't here, the doctor's not available. You know you just can't, you probably don't have your regular staff, that's right. So if there is **something there in black and white** that says 'This has been decided from a case conference', then if so and so becomes sick this is [sic] **the steps to follow**. ... //... the fact that it is there*

*and that you have everything in place, it actually **saves you a lot of time**, yeah ... It makes it **easy, it saves time**, you don't get stressed and worried that you are not doing what you should be doing for this person because it is **all there in black and white**, you are doing what is said and it has been agreed on by everybody so you don't have that angst about 'oh should I, shouldn't I, should I, shouldn't I?' because it has been agreed on so it is there. I think as a RN, especially an agency RN, I would be quite happy to have those sorts of decisions made for me, especially the agency nurse doesn't know the family, doesn't know the person. So that makes it even more hard for them (RN 23: Krys).*

The ACDs or POT resulting from ACP were not the end of the story but the base line from which to clarify and discuss more openly what the residents or family members would want at the end of life. The RNs talked through, with the family members, the issues that concerned them and the family. Katrina emphasised how ACDs documented made a positive difference:

*Oh I would say it (ACDs) is good you know. I know, I feel much more comfortable, I know that I can **talk about certain issues** with Kyma because, like for instance, with Kyma I would say 'Well we are not sending mum off to hospital as that's what you want and we agreed that that's the best thing'. We can **discuss her care more openly** by, when one of those options is not an option. So I actually prefer it, I like it much better with those guidelines. ... //... I, I don't think that, I haven't seen any negative outcomes myself ... //... if you know that the relatives has [sic] stated what they want, yes. It just makes things, **it clarifies things**, I feel (RN 26: Katrina).*

#### 4.3.3 Person-centred care (PCC)

The ACDs and POT through ACP generated clear directions that reflected 'Person-centred care (PCC)' (National Ageing Research Institute, 2006). PCC in the ACP process suggested a new way of understanding what a procedure or a treatment could mean to an individual or a carer as illustrated in the following Narrative.

##### **Narrative 29: What we do is an absolutely person-centred care**

For example, a simple common procedure from a doctor's point of view can have a detrimental effect on a carer when there is a failure to explore what the procedure could mean to the person and the family, and how it could affect their life on the personal level. The procedure or the treatment performed can be denied, with minimal positive outcome achieved. ACP is a process that ensures that the person and/or the family have been given the opportunity to express why they want or do not want a treatment, what life could mean

to them with/without the treatment and how it could affect them not only at the functional level but also at the psychological and spiritual levels within the person. The reasons, values, concerns, worries, and meanings expressed were then reflected in the ACDs/POT, which are consistent with a person-centred approach. Hanna provided an example in that:

*Take for instance (the) PEG tube. 'Oh we can just put a tube into their stomach and we will use that to feed them'. Maybe it is not the doctor's job to think about the ramifications of that. I had one carer come to me having spoken at, you know, to carers about the decisions they might be faced with. One carer came up afterwards and said 'You know the doctor told me that putting a PEG tube in was really a minimally invasive procedure and it wouldn't take long and it was quick' and it didn't go anywhere near the sorts of things that, in fact, **impacted to the extent where this wife decided to take the PEG tube out.** She said it blocked so many times, it was always leaking, they were always fiddling with it, it had to be resited, you know. At one point it dislodged and he needed to have his abdomen, he had to have a laparotomy to get it out, which I thought sounded a bit difficult to understand. Yeah so they had, she just said for something that was, as a procedure it wasn't invasive but **in terms of how it impacted on our life, it was a major invasion. It was very invasive.** So it is sort of again, language about what's invasive and what's not. But procedure yes, pin prick, pop it in or light anaesthetic, we flick it in and it is done, it's there and then it just sets up .... I mean sure there are PEG tubes that go in, no problem, people feed themselves with PEG tubes, you know, that's fine. But **it is looking at all the risks and the reasons why we put it in.** It (ACP) is a whole new way of approaching how we care for people at an individual family and society level and also clinician team and organisational level. Um, the good proactive quality of life that's anticipatory and it's **absolutely person-centred** (RN 25: Hanna: CNC).*

Katrina highlighted that the end-of-life care wishes identified in ACDs through ACP were person-centred not only because the wishes were expressed by the person or person responsible, but also the care delivered would be exactly what the person would have wanted.

*I thought that looking at Advanced [sic] Care Directives, where the person, even though the person has lost their cognition, their wishes are still able to be upheld, and I thought that was quite important. ... //... I think that the person involved, it **allows the person to have their wishes upheld** even though they're not able to express them, and I think that's good. You know it gives, you know, I mean it is about **personal consented care** isn't it, which is what we are all wanting to achieve, and it would give them some level of comfort, as they do decline, to know that that's there, that they have got, that their wishes will be upheld, and you can even say that to them 'Don't worry, we know what you want, we know how you want us to treat you later on and that's exactly what we will be doing. **Exactly what you want is what we will do**' (RN 26: Katrina).*

Krys made an important point that in ACP, even the care delivered to the residents with cognitive impairment would be what would be the best for the person, as the residents would be represented by the person who knew them the best.

*I think it (ACP) is, it's a good, it is a worthwhile thing to do. They still have a representative, a person who can speak for them, who knows them really well usually. The husband or the wife or the daughter, son, you know, **they know the person really well** and people do ... They want only **what is best for their person**. I don't see how it ever can be bad to keep someone comfortable. You know, I can't see any situation when it would be a bad thing to make sure they were pain-free and not suffering. So I think if the person could tell you, they would probably say that: 'I want to be comfortable, I don't want to be in pain'. Acceptable for them so they see their person, they're not in pain (RN 23: Krys).*

The positive outcomes of ACP in PCC were highlighted when the nursing staff encountered the outcomes of having no ACDs/POT. A number of examples that juxtaposed the positive outcomes of PCC were reported by the nursing staff. Krys brought up an example of a son who refused to take part in ACP and who kept sending his mother to the hospital at any cost. The son denied the opportunity to explore and discuss the care options that would have represented what his mother would have wanted. Therefore the care delivered was not person-centred but person-responsible-centred. Krys was resentful when seeing the outcome of the rejection of PCC for the mother, as the son was not the person who knew his mother the best and did not act upon what was the best for his mother.

*There was one person who had his mum sent backwards and forwards to hospital, practically weekly, she was diabetic and really unwell and really unhappy and really confused. She had dementia as well. He couldn't let her go so he kept getting her sent back to hospital. We couldn't get to a case conference to have any sort of agreement because he wouldn't go. No, every time anything happened to his mother, back to hospital. Some people just can't cope with ... I mean keeping her back and forwards to hospital, maintaining her life, was not doing her any good, it wasn't for her benefit, **it was for his own**. Sometimes I think you have to actually say that to people, you know 'Why are you doing this, are you doing it for her or for yourself?' you know 'I know it is hard to let go but ...' (The son said) Well **I am not ready**, no she's .... But people sometimes I have said that to and they have come around to thinking 'Yes well when you sit down and think about it, it is maybe, maybe it is mean.' Well people have admitted it to me too, 'Maybe **it is just for me, I am not ready**' (RN 23: Krys).*

Although everyone had the right to make their own end-of-life care decisions and the outcomes of having no ACDs or POT were clear, not everyone wanted to participate in ACP. The persons' or family members' wishes not to participate in ACP were also

respected. The reasons for not wanting to participate in ACP could not be elaborated in the current study, as they declined to discuss these further with the researcher.

#### 4.3.4 Dying with dignity

Another outcome attained through ACP was ‘dying with dignity’. It was important for the participants that the dignity of their loved ones was maintained at the end of life and they were able to achieve this goal in writing ACDs/POT through ACP. ‘Dying with dignity’ would be everyone’s right and everyone’s wish for anyone. However, where there was no chance to express what an individual wanted or did not want through ACP, the dignity of the person was compromised, as projected in the following Narrative.

##### Narrative 30: It is a dignified way to go

The ACP process made it possible to identify who the person was and what dignity would mean to the person. Written ACDs/POT ensured the person’s dignity as the essence of self and quality of self-respect were adhered to at the end of life. Kyma and Tess related how much dignity meant for them and for their loved ones:

*Oh nobody would want anyone to **die without dignity**. I don’t think, I don’t believe anyone would* (FM 20: Kyma).

*I think people should have the right to choose when, in a terminal situation, rather than just go downhill with **no dignity**. There is **no dignity** when you go down hill like that slowly* (FM 8: Tess).

Freddy believed that his mother Connelly had already lost her self-respect a great deal, due to dementia, however, the loss of dignity for Connelly would be minimised by preventing her from being sent to hospital where her undignified life would be prolonged.

*What we are really looking for is for mum to be able to **go with dignity**. Not being rushed off somewhere where she knows nobody, no one knows her and then she will probably go in 48 or 72 hours anyway. But all alone, it would be good for her to go where she has been for the last couple of years. We think it will ... at the end of the day it will get, you know, probably she will lose enough dignity as it stands but it will give, it (no hospitalisation in POT) will mean **less lack of dignity** at the end* (FM 22: Freddy).



The RNs defined repetitive hospitalisation, which would result in death sooner or later, as an undignified way of treating someone at the end of life. They confirmed that the residents would be able to end their life with dignity when the wish of 'no hospitalisation' was written in ACDs/POT and upheld by involving a hospital team, such as the PACS team in the facility. Katrina said:

*... even they **retain the dignity and they retain autonomy**, even at the end of their life. And who knows that they don't know that their wishes are being upheld. I just think it is a good thing, you know, **it is dignified** (RN 26: Katrina).*

#### 4.3.5 Change of culture and attitudes toward discussing dying and death

The data collected revealed that a change of culture and attitudes toward dying and death would probably be the most significant outcome of ACP. The reluctance and hesitancy to talk about dying and death in our culture was considered as a major barrier in the ACP process. Dying and death were always forbidden topics to talk about not, only for the families but also for the nurses, especially in RACFs. However, the data, as evidenced in the following Narrative, suggested that there had been a change.

##### **Narrative 31: I started thinking about end-of-life care and talked to my family**

One of the most significant outcomes of the ACP process was recognised in that the ACP process prompted people to think about what end-of-life care options they had, whether they would want it or not, and what the consequences would be of having or not having the treatments. The positive outcome of ACP is also noted in enabling an individual to express end-of-life care wishes, feelings, worries and concerns. Carla shared her experience with the changes in culture and attitudes as follows:

*There is **a discussion that takes place** on at what level, what sort of care do they want at certain levels of their life, depending on the quality. Do they want hospitalisation, do they want this or that? What do you want? Have you chatted with them? Talk to them. And really **enable the person involved to express**. ... //... So it's for the family to honour the wishes, you know, and if they haven't said anything, say, they come in with severe dementia, to think about whoever has got the guardianship role to think about, and have a talk to the other family members and say, what do we want to do here? ... //... How can I tell you what my mother wants? I can't, so I won't say anything, you know, in case it's wrong. So I think it is not as black and white as it*

*sounds. But I think things can be helped with, by **starting conversation** and even people talking about what their concerns and things are and trying to do what's best (RN 3: Carla).*

However, it was interesting to note that the change of culture and attitudes toward the discussion about dying and death were so distinct for those families who took part in ACP. They were more comfortable and prepared to talk about how they would want to die. Theo said:

*In my situation I have now, you know, with my dad (died) and with my sister (may die) some time and she has this (plan of treatment) and my grandmother (died) two years ago. So I am more comfortable to talk about that (dying and end-of-life care options) type of thing now. It is not, **it is not overwhelming and it's um, I am not, I am not scared of it** (FM 14: Theo).*

In fact, they were open enough to initiate the discussion of how they wanted to die within their own family, as Ray explained:

*But in my, now that I'm, having gone through this (ACP), I've just told my family that I don't want to be in that situation, you know, don't, never mind whether I've got dementia or not, I've already said I am not prepared so don't, you know, don't keep me alive. You know what I mean, sort of thing. Don't keep me alive. Yes, I don't want to be in that (my mother's) situation and I know my wife doesn't either. So you know, I am making sure my family doesn't have to go through that decision. I actually **discussed these issues with my family** because I've gone through this. I have done it with my wife, yes. So you know, eventually if I get in the situation, she knows, she knows and she can tell the kids that it is not what dad wanted. I mean I am not even 60 yet but I am making the decision already. You know what I mean and that's it (FM 16: Ray).*

Freddy also admitted that his experience with ACP for his mother was the driving force of the discussion he had with his family with regard to what he valued in life and how he wanted to be treated at the end of his life.

*So this (my mother's POT) kind of initiated the discussion for myself with my children. Yes, we didn't really have a long discussion about it but we just sat there and **talked about it**. It is not the way I want to go. I would like to think I could do things to stop it happening that way for myself (FM 22: Freddy).*

The change of culture was also noted among the nurses. Suzie, who is an RN herself, has had the discussion with her family and noted that her family also advocated what she wanted to achieve by doing it.

*Look I think it is, **personally I've done it myself.** I've spoken to my family, I have spoken to my children and I have said ... this is what I want and I want you to abide by that as much as possible please. Don't keep me alive if my quality of life is not good, just let me go. ... //... This is my life so I should have a decision on how I want to live it or how I want to die. If I have a heart attack at 48, yes try and revive me but if I am not going to come back and I'm not going to be okay, just let me go, you know, don't keep me alive for the sake of keeping me alive please, because I don't want to be like that and Tracey (my daughter) said 'Mum I will let you go'. (laughing) ... //... I don't want to be like that Sarah, **I just don't want to be like that. Not for myself or not for my family.** So no I don't see any negatives. Like I said, if it's, you can make your own decision, you are of sound mind, you can make your own decision, it is not under duress, I mean go for it (ACD), go for it (RN 24: Suzie: DON 3).*

### Narrative 32. We want to discuss our choices

The impact of past experience with death and dying, and the impact of current experience with ACP were clearly noted in the change of perception and attitudes toward end-of-life care discussions. The data collected revealed how the experience of people with ACP led to the change of culture about death and dying. The participants realised that the discussion about ACP process was not simply about death, which people were scared about, as they had no control over it, but it was about having more choices and controls in the journey to the death and in the way of dying. Krys said:

*I see people, people and their families **having more of a choice** with what happens to them because they, they would probably prefer not to be there and giving them more of a say in what happens to them. Surely it's their right, they have **right to choose how to live**, so they should be allowed to choose not to be kept alive or whatever (RN 23: Krys).*

Another explanation for the change of perception and culture was that the participants were slowly and little by little led into the most significant sub-element of practice in ACP, which was the 'discussion'. The participants who had opportunities to discuss how an individual lived life, what s/he valued, and how the person had made decisions in the past appreciated the chance to talk it through within themselves, with their family members, or with nursing staff. They realised that it was not as difficult as they had thought to talk about end-of-life care options with the help of the nurses. The benefits of having discussions about themselves or their family were obvious when the end-of-life care wishes were respected. A new culture of 'discussion, discussion, discussion' was emerging through the ACP process. Hanna explained the benefits achieved through discussion in ACP, as follows:

*When they got sick or they died, they actually died in the facility without being transferred, that their needs were met. Generally everybody thought it went really well .... because it was **a plan considered process**, it wasn't a drama, it wasn't a big shock, they knew it was coming so it was easier that sort of people who would accept the talk. They (families) certainly had a sense of satisfaction that they had given some direction for their decision, substitute decision-makers, that they had given some thought, **they had had an opportunity to talk things through**. So for individuals it seemed to be a good thing and maybe just reiterate their values and the sorts of elements, things that would be important for their decision-maker to take into consideration when the need arises, if and when the need arises.*

*I think for a family, like in substitute decision makers, they've really sort of felt at ease and I think some of the RNs have too. **There's been something in place, they have had the opportunity to talk things through**. ... //... This (ACP) is just a tool that aids discussion and some things they haven't thought about but it just provides them a prompt for them to **go away and talk about as a family** and that's been a good thing too. I think it has just given them some reassurance that there's [sic] things, processes in place, they are not all waiting for a big drama and some emergency, for something they know is going to happen (RN 25: Hanna: CNC).*

The culture of discussion newly created as one of the important outcomes of ACP was highlighted in comparison with the outcomes of non-participation in ACP and therefore, the absence of discussion with the people involved. Heather shared her experience as follows:

*There was a conflict between two family members. It was difficult, one wanted more treatment and one (the other) didn't. And again, I think, am, they are ... I don't think it was satisfactory ... that person was sent off to hospital and ... very invasive type-things were happening, and so they did eventually, the hospital eventually sent this person back and she died here. But it wasn't very easy at all because we were sort of in the middle because, you know, we are, **you are caught in the middle**. That was emotional actually, it was quite emotional that one because you also cared for this resident and you know what you would like for them but you can't express that opinion. You have just got to wait for them to work it out. But you know that one person is sad and one is quite happy because they have got their own way, so it's hard (RN 5: Heather).*

## Conclusion

This chapter has described how and why ACP and the use of ACDs were implemented by the CNC in RACFs. The outcomes of ACP for residents, families, and the RNs have also been presented. The conceptual framework modified from General System Theory by Von

Bertalanffy was used to help draw a montage of implementation of ACP in RACFs. It was clear that there were requisites for nurses to initiate the ACP with the residents and families. It was only a legitimate and professional solution to implement ACP when the quality of life of residents and the family members was diminished, due to deterioration and repetitive hospitalisation that caused prolonged life with suffering. The expert nurse and the nursing staff in the facilities were motivated by the belief that the residents and the families had a right to choose or refuse treatments at the end of life and that nurses had responsibility to respect the decisions made. All three RACFs had policy and manuals on ACP and ACDs to encourage and support the staff to get involved in ACP and the use of ACDs for their residents and family members. Given that there is no legislation with regard to ACP in NSW, the nurses used the Guidelines developed by the Department of Health to safely practise ACP within the legal boundaries. The CNC was recognised as a significant resource in implementing ACP and documenting ACDs and POT. She was the major driving force in the whole picture of ACP in RACFs.

With the help of the CNC, the RNs in the facilities worked hard with and through a number of sub-elements. The paperwork for ACP and ACDs/POT were set up in facilities. The discussions with everyone involved in the care of residents were organised through the case conference. Education sessions were crucial in the ACP process to empower and enable people to be able to execute their right to consent to or refuse treatments. It might not have been possible to respect end-of-life care wishes if there was no support from multidisciplinary health-care teams in RACFs. Communication was essential in identifying what the person might want to achieve through ACP and in collaborating with the multidisciplinary team. However, it was noted that there might be a loophole in the process due to communication breakdowns. The expert nurse and the RNs were aware of the legal and ethical implications of ACP and the use of ACDs. The Guardianship Board as a resource provided them with relief where there was a legal concern. Interestingly, the participants' opinion on the best time for initiating ACP discussion was varied. They all agreed that ACP was important to promote health and well-being at the end of life and everyone should be offered a chance to discuss this on admission. However, it was strongly mentioned that the discussion should occur before the older person lost her/his capacity. The expert nurse and the RNs had experienced a number of difficulties: a taboo on talking about death and dying, lack of commitment from staff, high turnover, and difficulties with abstract thinking.

Nevertheless, all participants strongly believed that ACP and the use of ACDs/POT had resulted in a number of positive outcomes. The residents' and family members' end-of-life care wishes were written and respected. The written directives provided the nursing staff with clear directions about what to do in the care of older persons. ACP was considered as absolutely person-centred care which promoted dying with dignity. The participants realised that ACP had impacted on not only the quality of life of the older person by respecting end-of-life care wishes but also on the change of culture and attitudes about death and dying. The family members and the nurses started discussions with their own families about what was important to them, what they valued in life, and how they would like to be treated at the end of life.

In the following chapter the experiences of residents, family members, and the nurses with ACP and ACDs/POT, and the scope of nursing practice for the expert nurse and the RNs are presented.

## Chapter 5

### The Findings: Part Two

#### Introduction

The phenomenon of ACP in RACFs was investigated by proposing four research questions. Chapter 4 presented how the data collected clearly revealed the manner in which ACP was implemented in RACFs. It also outlined the perceptions of participants about the outcomes of ACP for residents, families and the nurses. The elements and sub-elements in the relation to the process of ACP implemented by the CNC in RACFs were described. The process involved inputs that were essential to initiate the ACP program, throughputs that the participants needed to work with/through, and outputs that were generated as results.

The investigation of the phenomenon of ACP also included another key question about what the residents, family members, and the nurses would experience with ACP and documentation of ACDs/POT, as such a question had never been formally posed to this group of people who were most intimately involved in such a sensitive and personal set of circumstances. The last research question, on how the scope of practice in ACP was perceived by the CNC and the RNs in RACFs, was critical to examine, in order to identify the implications of current practices of ACP for nurses and in nursing practice. Chapter 5 presents the findings related to these two research questions.

The data, in an attempt to answer the above questions, included the written materials collected from the interview transcripts, the field notes written during the observation periods, and the documents reviewed. The data was gathered and highlighted using CIT where, needed for further extensive thematic content analysis. Narratives are chosen to describe situations in which the participants expressed their feelings, emotions, concerns, worries and difficulties with regard to ACP, ACDs and POT. Each narrative represents a theme or themes drawn from the CIT and thematic content analysis.

There are two sections in this chapter. The main purpose of 5.1 is to present all the narratives captured in relation to the issues raised by the research questions regarding how

residents, family members, and RNs perceive their experience with ACP and ACDs in RACFs. The researcher developed the framework questions (see Appendix 18) in order to reveal a full appreciation of their experience with ACP in RACFs. Section Two describes the current level and extent of participation of nurses in ACP, and the scope (the range, depth and breadth) of the roles and functions of nurses in RACFs.

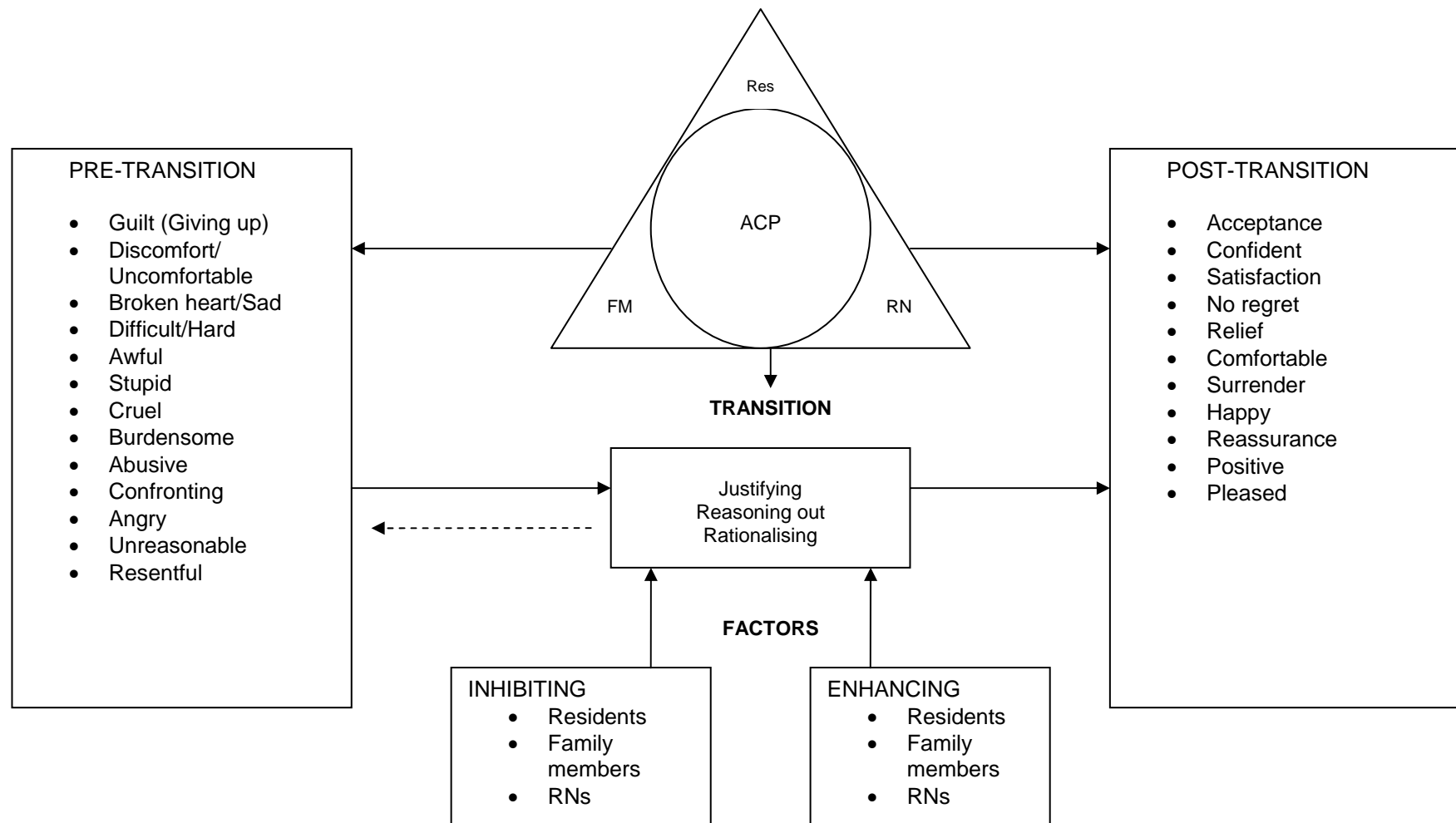
### 5. 1 Experiences with ACP

The experiences of residents, family members, and the RNs with the ACP process were revealed as themes in the narratives and projected as one of the four images in the montage of the phenomenon of ACP. The following section describes the image of the experiences of residents, family members, and RNs with the ACP process that was drawn from the excerpts and narratives. The image that portrays the experiences of residents, families and nurses with ACP is depicted in Figure 5 – 1.

The elements of the conceptual framework depicting experience with ACP and ACDs are: pre-transition, transition and post-transition. There are enhancing and inhibiting factors affecting the transition phase. The participants who were involved in the ACP experienced various feelings and emotions. The words mentioned by the participants to express what they went through include *guilt, discomfort, denial, sad, difficult, awful, cruel, burdensome, abusive, confronting* and *resentful* in the pre-transitional phase. These negative feelings and emotions were then transformed to expressions containing words that represent a more tranquil ‘esprit’ when the participants arrived at their journey’s end through ACP. Those words included *acceptance, satisfaction, relief, comfort, surrender, happiness, reassurance* and *positive*. It was clear to the researcher, however, that both enhancing and inhibiting factors were evident in the transition phase. These enhancing and inhibiting factors are listed in Table 5 – 1. The following discussion elaborates on these phases of transition, with excerpts from the data as illustration.



Figure 5 – 1. Conceptual framework for experience of residents, family members, and RNs with ACP



**Table 5 – 1. Factors influencing the transition**

	Enhancing Factors	Inhibiting Factors
Residents	<ul style="list-style-type: none"> <li>• It's just me. (Essence of being)</li> <li>• My right, my responsibility (Autonomy)</li> <li>• I had a good life. Use the resources better (Transcendence)</li> <li>• Religious belief</li> <li>• Why prolong? No point!</li> </ul>	<ul style="list-style-type: none"> <li>• Difficult to understand medical aspects of treatment options</li> <li>• Where to draw the line</li> <li>• Fear of my wish not being followed up and not being heard</li> <li>• What family wants</li> </ul>
Family members	<ul style="list-style-type: none"> <li>• Mum/Dad had a good life. Use the resources better. (Transcendence)</li> <li>• What is the point? (no QOL, no dignity)</li> <li>• It helps that I can revoke it.</li> <li>• The involvement of hospital care team (PACS and Palliative care) in ACP was good.</li> <li>• Not for me but for mum/dad.</li> <li>• Back-ups from other family members and nurses.</li> <li>• The impact of past experience with dying and death.</li> <li>• I wouldn't like it myself.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of explanation</li> <li>• No back-ups</li> <li>• Guilt (giving up)</li> <li>• Not PCC</li> <li>• Lack of family involvement in care</li> <li>• Not being followed by family member (family in denial)</li> </ul>
RNs	<ul style="list-style-type: none"> <li>• It is their sense of who they are.</li> <li>• It's not euthanasia.</li> <li>• Giving them choices &amp; control (Autonomy)</li> <li>• Promote dignity and comfort</li> <li>• Person centred care (PCC)</li> <li>• Respecting wishes</li> <li>• Back-up from family members and other nursing staff</li> <li>• Providing reassurance to the residents and family members</li> <li>• The involvement of hospital care team</li> <li>• Helping them to be, essence of being</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of discussion</li> <li>• Not being followed by family members (family in demand/conflict)</li> <li>• Culture of 'do everything'</li> <li>• Culture of 'don't go there'</li> </ul>

### 5.1.1 Pre-transitional status

It was clear that some family members and the nursing staff experienced ambivalence in taking part in ACP, as they considered the decision to be made as either ‘letting go’ or ‘letting suffer’. Trish, the daughter of Nina who is 90 years old and whose health has been fluctuating, felt awful and stupid not only to document ‘no’ for active treatments but also to let her suffer by not saying ‘no’. Trish recently had documented ‘NFR’ and ‘no hospitalisation’, and ‘no tube feeding’ after lengthy discussion with the GP, the DON, and the RNs. She was confused and struggling to accept the reality of the decision she had to make. Trish thought:

*It is just going to be like this to the end now, we are going to have a good day and we are going to have bad days, you know, but I told the doctor and the nursing-home here that if her heart gives way and she goes, I don't want her revived and I don't want a feeding tube in her stomach. So ... I don't know how, I **feel awful** about that but I don't think it is necessary you know. If she just passes on comfortably, I don't know, I don't know ... As I said to the doctor, I don't know... I feel really **stupid**, you know what's the next step. God I don't know, I feel really stupid. (upset) ... //... But I, I just, my wish for her is for her to just die in her sleep, peaceful, just go but I think she can't do it. I think she's just going to have more and more deterioration and it's going to get harder for her and she's going to suffer more. I just **think it's awful** (FM 11: Trish) .*

Trish was the only child of Nina. Her father has suffered from end-stage heart failure and had mobility problems, hence she was the sole decision-maker in Nina's POT. Trish was asked how she would describe that experience and what went through her mind. Trish said:

*It was **difficult** but I, once again I think it's the reality of it. For what? ... (thinking and sighing) ... a little bit **difficult** I suppose. The main thing that went through my mind was, I want her at peace and ... //... before I made the decision she (the geriatrician) said 'You have to let go'. I said 'I know that, I know, I know' and I do know that ... but it's just **difficult** (swallowing her tears), **extremely difficult** to make but in reality you have to make them, someone has got to do it ... //... she's ... it **breaks our heart** to see her the way she is. ... //... You've got to take the responsibility and do it. It is not something that you take lightly. It **breaks ... my heart** (crying) ... to make them, but in all, all facts, you know, there's no future (FM 11: Trish).*

The nursing staff had expressed great sympathy for Trish and many other family members. Katie expressed her feelings that:

*It is **awful** to say they (family) want them to die but they don't want her to go on, you know. It is an **awful** thing for her to be ... I don't know (RN 13: Katie).*

Tess, who was the person responsible for Vincent, also had similar issues. Vincent was born in Egypt and immigrated to Australia with his wife 50 years ago. His wife died of cancer seven years ago and Tess had been Vincent's closest friend for the last six years. Since his Motor Neuron Disease (MND) had worsened, Tess managed his financial affairs and was also asked by him to make medical decisions for him. She had been involved in his hospitalisation a few times and relocating him into the nursing-home. As Vincent had expressed to Tess frequently that he would not want to be kept alive or sent to hospital, she felt burdened with the responsibility. Tess said:

*I felt kind of, sort of responsibility to look after Vincent ... I did, I did, I did because he gave it to me. I mean if somebody gives you fully power of, Enduring Power of Attorney and Executor, of course. It was, **it was a burden**. It was a lot of responsibility. **It was a burden**. Of course it was. ... the responsibility of the whole thing* (FM 8: Tess).

Laura who was the niece of Mary was confronted by the Doctor who told Laura the consequences of Mary having CPR to her frail body at the age of 92. Laura expressed her feelings that:

*Yes, the decision of having Advanced [sic] Care, that was **confronting**. Doctor Tham said if she had cardiac pulmonary resuscitation it is likely that they could break every bone, every rib cage, every rib in her body and we thought 'we don't want that'* (FM 19: Laura).

The feelings and difficulty experienced by Laura were somewhat different from those of other participants. Laura and her father, who was the younger brother of Mary, were encouraged and left by hospital staff to discuss end-of-life care treatment options for Mary. They found that the conversation did not go far, as they did not know where and how to start. They did not understand where Mary was at with her dementia and where she was heading.

*I tried to discuss it with dad a couple of times and he says 'Oh this is really **difficult** Laura, you don't know what is going to happen. I think we have got to get advice on this'* (FM 19: Laura).

Ray, as the only child of Lily, reported that he had suffered a great level of guilt when he had to put his mother in this nursing-home. However, he coped with the guilt and believed that his mother was in the best place to be. Ray went through the same process when he

made the decision to refuse any aggressive treatment but the need to keep her comfortable and pain-free in the nursing-home. The initial guilt with uncomfortable feelings was hard for him to deal with. Ray said:

*I also thought that same way before she came into the nursing-home because I felt like I was **giving up** on her then, you know, and I sort of reasoned that out. I said 'Well' at that time I sort of went through it and I thought well I'm not actually giving up because I've done as much as I can and I just can't ... //... I would think everybody would feel the same. I cannot imagine anybody not feeling that way in some way or the other, you know, that they'd **given up**. ... //... 'Okay I have to give up something' because I feel like you know, it's kind of **discomfort** or **uncomfortable** feeling when you have to **give up** something. ... excuse me (he was weeping and dried his tears) (FM 16: Ray).*

Kyma's mother Joy had both vascular and Alzheimer-type dementia. Joy had not responded to any stimulant at all for nearly two years. Joy has completely shut down herself from the world around her. She occasionally took pureed food but her mouth was mostly clenched shut. She did not interact with anyone in any form of communication channel. Kyma had lived with her mother for all her life. Kyma said that her mother and she were very close, like sisters. Kyma made a statement saying that her mother should not be sent to hospital, should not be force-fed with any artificial measures, should not have attempted resuscitation performed on her, and should be cared for in the facility. Kyma swallowed her tears and showed her brave face when she mentioned the following.

*It's ... it **breaks my heart** all the time but you know, I have to be strong because there's only me and if I fall apart there's nothing. You know, I have to be here to say, you know (FM 20: Kyma).*

Interestingly, it was only the families and the RNs who reported experiencing those difficult and negative feelings and emotions. The resident themselves did not report sadness or discomfort about their own decisions. It was obvious that the residents had already attained calm and peace in their minds. The depth of analysis of this finding is discussed in Narratives 33 and 34 in 5.1.2.1 Enhancing factors.

### 5.1.2 Transition

The participants were able to transit from the negative feelings and emotional turmoil to the stabilised contentious status through justification, rationalisation, and reasoning out.

For example, Ray mentioned that the guilt and discomfort that were with him all the time have eased through the process of rationalising his decision.

*Well see, I don't feel so much like that (guilt) anymore because I've **rationalised** it so.... It is still there, you still have that in the back of your mind but ... I am much more comfortable with it, you know, than I was at first. I was very **uncomfortable** for some time, you know, **very uncomfortable** about it ... well for that reason, I thought I had **given up**. ... well as we said before, you know, you feel like you've **given up** and just giving your mum away, you know. That's not the case really when you, when you go through it, **when you rationalise it in your mind**. Well just, I think, bloody same thing so like what I was doing was just no good. I just thought well, as I said, I don't think I would want to live in that situation (FM 16: Ray).*

The participants used various ideas, beliefs, values, and attitudes in their transitions, which were reflected in the narratives. Each group of participants required different factors to enhance movement from a pre-transitional emotional turmoil to a stabilised post-transitional status. They also reported different factors that inhibited the more positive transition and those that may have forced them to stay in a pre-transitional stage. The factors influencing the transitions are now elaborated in the following Narratives.

#### 5.1.2.1 Enhancing factors

##### Narrative 33: 'Essence of Being' was enhanced through ACP

The residents, family members, and the RNs all felt strongly that *the essence of being* – who the resident was and how s/he has lived life – was enhanced through the ACP process and it became one of the most important factors for justifying their participation in ACP and to transit the negative feelings and emotions to positive thoughts (see Table 5 – 1).

The residents who had made decisions to document ACDs and who were interviewed mentioned that 'it has always been me' who 'planned ahead', 'controlled my life', and 'not looked back once the decision was made'. They reported that they felt respected as who they were. They were satisfied that the end-of-life care wishes discussed and documented would be followed. The essence of 'who they were and how they lived their life' was not affected or disrupted by their new identity as a dying person, rather it has been enhanced through the ACP process and documentation of ACDs.

Jill was a 78-year-old lady who was once told by her doctor that she had only three months to live 10 years ago. She had encountered death in a quite dramatic way for the first time but survived. She was traumatised not only because of her imminent expected death at that time but also because of the realisation that she could die like many others. Jill, who liked to plan and organise ahead, felt anxious about the fact that she had not prepared for her death and it was simply not her. She needed to feel prepared and ready. The core quality of Jill's being, who she was, was achieved through participating in ACP, which allowed her to live her life to the full. As Jill said:

*I like to have things planned and ready. ... **I was always like that kind of a person, you know once you decide, you don't look back and ... yes, oh yes, make the most of it. You know, his (husband) cup's always half full, always, mine's not, mine is up there (full) ... //... I suppose it is my nature, always has been. Make the best of things, yes. Therefore, you are not going to be disappointed or anything else. ... No, it is no use regretting, you know** (Res 18: Jill).*

Morton, who was a dress-maker described himself as a 'beauty'. It was essential for him to maintain his physical appearance and functional status as presentable in order to be himself, and that was how he lived his life. Given that he experienced his sister's horrific death, he wanted to ensure that he would be remembered as who he was to his family and friends by documenting his end-of-life care wishes in his ACDs. The essence of being himself to the last breath was therefore to refuse any artificial measures to prolong his life when he becomes cognitively unaware and loses basic bodily functions. He felt reassured, satisfied, comfortable and happy with the decisions he made through ACP. He did not have to be someone who he was not at the end of his life. Morton said:

*I think anybody who wants to be sick must be out of their minds. Really I do. If you don't get much out of life, what is the point? I really see no point **so that is me.** ... //... I want to die a beauty definitely. I mean being born a beauty I want to die a beauty. Oh no thank you, doing things in your pants. I couldn't, I would kill myself. I really would. Awful (he was shivering his whole body emphasising and expressing how strongly he felt about incontinence). And I know that people don't. I used to see them where my sister was in here the hostel you know. I used to go and see her and some of them, she was probably older than most of them but she never did, never became, she never dribbled or did anything like that and she was made up all the time by herself. She looked after herself very well while she was still capable but towards the end when she was no longer capable, I didn't really want to see her. ... well ... because she was a beauty ... and ... (swallowing his tears) it wasn't her. And I find that very distressing so I don't want my friends to see me like that. That's about the size of it. I suppose that is vanity but I don't think it is, **I think it is self-respect, myself.** I can't bear that (Res: 21: Morton).*

As the residents felt that their essence of being was enhanced with ACP by letting people know who they have been, how they lived their life, and what they wanted at the end of life, the RNs also agreed that they believed the ACP helped the residents. Helping older persons be who they were eased nurses' negative feelings and justified their involvement in ACP. The residents' individual end-of-life wishes were not unpredictable and were fairly consistent with their values and beliefs that had made them who they were for all their life. Therefore, ACP is definitely person-centred and the roles of the RNs involve identifying who the person has been, drawing out the person's end-of-life care wishes, and ensuring their wishes are upheld. Hanna said:

*I think nurses would feel like that they have done their best because they've got that values history, they've got that to know, 'Well this is what is important to this person ... //... And I mean I don't talk about, I mean religion can be from some of the considered faiths but, for a lot of people there is an element of spirituality that's got nothing to do with religion at all. **It is their sense of who they are and the meaning of their life and what would be important to them at the end of their life and maybe after they've gone.***

*Some of them had done it three months before and so they were coming back for their review meeting and they go 'No, there's nothing I'd change, in fact, you know, so (their end-of-life wishes are) **fairly consistent**, yes ... Yes I mean if people have life changing events in their life, their values might ... I suppose their values do change but it probably more enhances their personal values than maybe the material values that they might have had beforehand. ... //... yeah, I guess if someone is going to try and enhance your meaning of life and your experience of life, if you can't do that for yourself, then I think it (ACP) is our only alternative really, isn't it? (RN 25: Hanna: CNC).*

It was fascinating to identify a clear pattern that most of the family members mentioned that their decision to participate in ACP and to document ACDs/POT was to respect who the mum/dad/sister/aunt had been and how they had lived life. The ACP has helped the family members to identify the essence of their loved ones and enhanced their feelings of satisfaction, relief, happiness, and comfort by ensuring what their mum/dad/sister/aunt would have wanted would be done. They wanted to make sure that their loved ones would be not subjected to life-prolonging measures simply but definitely because it was not her/him. In fact, Bev's mother Marjorie had mentioned that in the past that their life should not be maintained with life-supporting equipment. It was noted that Bev justified her decision to document her mother's wishes in POT and her sadness and discomfort in



documenting ‘no hospitalisation’, and ‘NFR’ were transited by letting her mother be who she was to the very end stage of life. When Bev was asked what helped her feel better about the decisions she made, she said:

*What you are seeing with mum now is completely the opposite probably to what she was, and she wouldn't like to be like this either. She would tell you herself, in fact she did, about a year before she had the stroke and I was over there and she was watching a documentary or video with, Kirk Douglas, who had just got over a stroke and she turned around and said 'If ever I turn out like that, I don't want to live'. And not long after that she actually had a stroke. ... //... you know, mum has always been the type of person is, you call a spade a spade. That's it, you know, there's no this, there's no that. A spade is a spade, no matter what. You know, you get over it and **this is the way she is**. That's life, that's death. ... //... the decision would have been the fact that **mum would not like to see her in that position, she wouldn't like, she herself wouldn't want to be resuscitated**, because the same thing I said before with the stroke business, **she doesn't want to be like this**. If she knew she was like this she'd probably take a bottle of pills. ... //... **So that decision was made based on her wishes in previous... her personality and who she was. That's right, yes exactly, yes exactly** (FM 17: Bev).*

Freddy, who was a well educated and intelligent person, was resentful about the kind of life his mother Connelly has had with dementia. It was difficult and sad for Freddy and his brother Scott to see where his mother was at. Freddy was heart-broken because of the suffering that his mother went through. They were well aware of their role as Enduring Guardians and wrote a statement to ensure their mother's essence of being would be respected by everyone who was involved in her care. Freddy believed that his mother Connelly, as a practical former nurse, would not have wanted her life to have been prolonged by technology. Freddy explained what helped his feelings of heart-break and uneasiness as follows:

*We (my brother and I) were pretty convinced that **that is what mum would have wanted**. With the power of enduring carer the obligation on the carer, the person with the power is to do what you think the person would have wanted done. That was ultimately the overriding factor. We were aware that as power of enduring carer we should be doing **what mum would have wanted**. We don't think mum would have wanted to be kept alive (artificially), when I say artificially, I mean when they would be dead if nature was left to take its course but you can prolong the life.*

*... (it's) difficult. We feel that mum has suffered a great deal, we also feel that if mum as I was saying before, 20 years ago could look at herself today **she would not like to be in the position she is in**. She would want to go with dignity. And she was a nurse herself and she was always a very pragmatic lady. I think, what we are saying here basically is that if mum were to catch pneumonia or something like that and it was life-threatening and it could possibly be saved by going to hospital taking her away from*

*the comfortable situation she is in, we wouldn't really be advocating that. We would rather she stayed here uninterrupted and just let things take their course. Give her the best possible care you can but no artificial extension of life. Even though I know that is a very grey area. We just think that is in **mum's best interest, what she would have liked.** ... //... We ... (thinking) ... We don't, even though mum has been well looked after, the quality of life leaves a lot to be desired. And again, we think had mum been able to see herself in this situation **she wouldn't have wanted to prolong her life unnecessarily** just using modern technology as opposed to technology she was familiar with. We just don't think that would be the case (FM 22: Freddy).*

Another factor that helped the participants with negative feelings and emotions is reflected in the following Narrative.

#### **Narrative 34: Transcendence: I had a good life, use the resources better**

As mentioned earlier, the residents did not express any sadness or discomfort discussing end-of-life care preferences, and the reasons for this were sought. The resident participants clearly experienced their spiritual domain, defining the essence of who they were and how they interpreted their life. It was noted that the residents' acceptance and comfort in discussing end-of-life care treatments derived from the sense of transcendence they experienced. In other words, they were at a state of being or existence above and beyond the limits of physical, functional, psychological and material domains. Their experiences of transcendence were evident in the high levels of satisfaction with their life, despite the functional limitations, the decreased social contact and the gradual decline in physical health. The transcendence they experienced was also reflected in their attitude of being above and independent from the focus on self by being altruistic and philanthropic in relation to the limited resources for health care in society. The residents reported that they were not interested in being kept physically alive by intensive medical technology if they lost their 'self-entity'. They would rather see the efforts and resources being made available for others who may need and benefit to a greater extent. Thus discussion about end-of-life care treatments did not cause emotional distress but did enhance their satisfaction with life and acceptance of dying and death.

For example, Jill who survived a terminal illness 10 years ago and who now lived in a hostel, appreciated the 10 extra years that she had been given. Jill defined 'being useful' as the core quality of herself. She was satisfied with her life because she was able to help others as a generous, giving person. She transcended her fear of dying and death with her

satisfaction in life by being an unselfish person. Her satisfaction in life and with herself was enhanced through ACP by documenting the treatments that she would like to refuse when she becomes not useful any more in her own sense. ACP gave her comfort and satisfaction, as she would be able to be the essence of being 'herself' even at the end of life, and as her integrity with benevolent attributes would not be disturbed. When she was asked if the discussion about end of life made her sad or uncomfortable she said:

*Well I've had a good life, I am ready, that's okay. ... //... Well, just the fact that I have lived my life, well presumably. If you get an illness that you think is terminal, which I did, well I'm, I've had a good life that's it, finished ... //... you think of all the lives that people have had and the marvellous things they have done and I don't feel as though I have done anything. (laugh). But again, it is because it is your nature, and ... I've often, often looked at all these people who (are) stars, especially women because you can relate to what their life might be and almost without exception, this is the, I can't even think of names now, but they have been single-minded 'I want' and just 'I', all the way. I've never (been like that), and that's got to do with upbringing and everything, you know, whether you think of you or whether you have always had to think of someone else ... What would be the use of it? Now I think now, the use of, **I like to be useful**. If I wasn't going to be of use to anyone, I am not interested. So **being useful... means a lot to me** (Res 18: Jill).*

Morton also expressed the view that he was happy with the life he had. He was a lawyer for his mother for a while but became what he wanted to be – the dress-maker. He had a wonderful partner for long time and was quite successful with his business. He was a man with wealth and enjoyed company of others very much. He was at end stage heart failure and had prostatic cancer with bone metastasis. His social activities had decreased because of his frailty. Nevertheless, he transcended all his material and social wealth to his altruistic attributes for a society with limited resources. The transcendence he experienced was the reason that he accepted his own death at some stage. He was content with the ACDs documented, as he believed they would prevent resources from being wasted on him in providing the treatments that he would not want to have. He explained why he felt comfortable with ACP:

*I would hate to die without seeing my dear friends ... I would resist that but apart from that **I am ready to go. I have had a good go**. ... //... I am 94. I have had a wonderful, wonderful girl and God has been very kind to me and I am very grateful. So I think if he says, you know, now is the time to get on your way you just obey. You have got no choice really; we know damn well we have got no choice. What is the point in kicking against it? You only make yourself tired and less pretty. ... //... The waste of money, when they could be saving some child who is having a difficult birth or something. They*

*have had a good go really the oldies, we have a wonderful go. I have no complaints not quantity and quality, no, I don't have any complaints* (Res 21: Morton).

Interestingly, the family members also experienced secondary transcendence, which helped them to transit. There was now a sense that they were in a phase of transcendence in which the family members believed that mum/dad/sister/aunt had had a good life. For example, the resident might have lived through a war, social changes, and personal crises that one might consider as a tough life. However, there was a great level of appreciation and satisfaction with life at this stage of that life. The quantity of life remaining was less important than the quality of life. The pursuit of quality of life for mum/dad/sister/aunt called out for a need for ACP. The feelings of discomfort, difficulty and guilt that the family members experienced during ACP were in transit on a path to relief, satisfaction, and reassurance with transcending as an enhancing factor. Bev shared how she became more comfortable with POT for her mother:

*We look at it this way, **dad and mum have had an extraordinary good life** ... they've done everything they have wanted to, they have travelled ...* (FM 17: Bev).

Laura said:

*Mary has lived 92 years, she's, she's lived through two wars, no three wars, four wars, great social changes, **she's had a good life**. The quality of her life will be deteriorating from now on, um, we would rather have natural means of her survival instinct to take over rather than any artificial means and that, that was the driving force* (FM 19: Laura).

### **Narrative 35: Autonomy in social context; my right, my responsibility but we all need back-ups**

Another interesting factor that enhanced the experience with ACP and ACDs for all participants was that ACP provided the resident with a vehicle to practise their right to choose what they wanted and how they wanted to be treated at the end of life. All the individuals as autonomous human beings not only claimed that they had the right to make decisions for themselves but also admitted that they had responsibility to own their right to choose. The residents wanted to be in control of their life and believed that it should not be left for somebody else. Jill said:

*So I've followed that along, don't let anybody else have to make the decision, you make it yourself and make it now ... //... Well I think I should, **I should be responsible.** I don't think anybody else should have to (make decisions) for anybody. ... //... Oh yes I think **I do have the right but I have the responsibility as well.** ... //... See our generation has always had it easy, the doctor or someone else will do it. ... //... But the pennies are dropping now, like the banks or anybody else, it is do it yourself, you know. My daughter Annie, if I wanted to make a Living Will she would be happy about that and if I say 'I want you to decide', I am sure but I don't think she should have to have that responsibility. ... //... Yes, that's another reason why it should be our responsibility because he's (her GP) had a huge heart attack, not so long ago. Why should he have to sit there worrying about what I am going to do, right? He's battling to keep going himself (smiling). ... //... I don't see why anybody else should have to (make decisions for me). ... //... Well I realise now how much things have changed and how many options they've got. So therefore **I am willing to take the responsibility myself** (Res 18: Jill).*

However, it was interesting to find out that the older persons as individuals also sought support from family members, although they mentioned that it was their right and responsibility to make decisions for themselves. Family members revealed that they wanted to be supported by other family members and health-care professionals, and be reassured that they were making the right decisions for their loved ones. The RNs also obviously noted that an older person or a family member would not take sole responsibility to control the end-of-life decision-making or they encouraged the older person and family member to discuss the issues with other significant members in the family. It proved that an individual as a social being would need support and confirmation from others in the social context that s/he was in to practise the right to make decisions. In other words, the meaning of autonomy was intensified and validated when the autonomy was practised/executed within the social context in which the individual was located. When Jill was asked if she involved anyone in ACP, whilst her willingness to do it herself was respected, she said:

***I've told her (my daughter) what we were thinking about that. She didn't say much, she just listened. So I'll tell her next week what we decide, she will be happy about that too. She would be happy to go along with what I wanted, she wouldn't try to change my mind about anything. I think she would just agree..*** (Res 18: Jill).

The sense of discomfort, guilt, and burden that family members experienced in ACP were transformed to relief, comfort, and acceptance by having someone in the family who agreed with the decisions made. Given that the extent and nature of the decision would result in life or death, the family members wanted it confirmed that everyone in the family was aware of the implications of the decision and asked their opinion. For example, Theo,

who was the main carer for his sister Tia with end-stage MS, took the burden off his shoulder by involving everyone in his family when he documented the POT for Tia.

*Yes, I mean those type of decisions (POT, palliative care only) like that, well for me, in our case you know, Tia couldn't talk so she couldn't say what she wanted, which is hard so, you know, the decision falls on us and I think that, you know, it is important that you need to canvass everyone's opinion, **you need to get all the family involved to see what they want**, because this is a decision of life or death here and you don't want to look back with regret. That's what has happened here, you know, in this case here, I did care for her, I was the main carer for her and **I was happy to lead that decision but I made sure that everybody was involved**, you know. Everybody brought into that idea because I don't want to, I didn't want to come back ... I knew it was the right decision but I didn't want someone to come back and say 'Well why did you do this, are you sure that was the right way of doing it?' ... //... Yes, for my sister I think that I am the main representative, and you know I mean, when it comes to decisions like, like how to care or big things like that, should we let her go or should we not, you know, I would, **I would consult my brothers and sisters about it and my mum of course to make sure that they are happy** ... I mean normally sort of come up, the question would come from me and then I would have to ask everyone (FM 14: Theo).*

Trish, who felt awful and confused about whether she was making the right decision about 'palliative care only' for her mum Nina, who had end-stage dementia and was bed-bound, sought her father's support. She desperately wanted to be validated by her father in that what she decided for her mum was what her father also wanted.

*I just feel, in my heart, that as long as she is not in pain (swallowing her tears) and she's comfortable, I think that's the way to go, I myself and **dad backs me whatever**, you know. ... //... some people might think that I'm mean by doing it, I don't care. **This is my decision and dad's, not just me alone. He's, he's agreed with me that, just let her go, you know. I think that's the best way ... for her and for us to cope with it** (FM 11: Trish).*

Ray, as the only child of Lyn, felt burdened and guilty when he had to make end-of-life decisions for his mother. The fact that the decision of 'no hospitalisation' and 'NFR' was made alone exacerbated his feelings of guilt. The support Ray had from the nursing staff and the GP in the facility substituted support from brothers and sisters who did not exist and he became more comfortable with the decision he had made. Ray said:

*Oh ... in a way they (the nurses) did (help me in making the decision) because they all seem to think it was the right thing, you know, don't feel upset or anything, it is probably the right thing to do. They were pretty much all pretty sympathetic, you know. I know Cheryl and I'm getting dementia here myself ... (trying to recall the name of the RN) Oh Carmel, Carmel yes (laugh) yes, yes ... **the staff here support you** ... yes definitely*

*did, yes. ... //... Well I feel it would have been better if I had had a brother or sister, like I could have you know, talked through it with. If I had had a brother or sister when then it could have been, it might have been, you don't feel so guilty. As it is the decision was totally mine, you know, I didn't have anyone else to share it with. ... //... as I said a shared decision is always a lot easier than a sole decision. ... //... I was sort of, up until then, still very you know, in two minds. I mean I had made the decision but I still wasn't all that comfortable with it. I rang, when I rang **Doctor McLeod** I felt even more, a bit more comfortable **I said that to my wife** actually. I said 'I think I've made the right decision' she said 'Yes you have'. So yeah, that was it (FM 16: Ray).*

The RNs noted that end-of-life care decisions were never made by one family member. There were always other family members included in the decision-making process. It helped them cope better with guilt, burden and grieving, even after death. Suzie noted that ACDs or POTs were usually co-signed by more than one family member. Krys experienced that:

*I think the most recent one when he passed away, **his wife was, she had come to terms with it already because it had all been discussed**, so she'd come to terms with it and she wasn't as distraught as she would have been or probably would have been if it hadn't all been discussed and she was ... **she'd also discussed it with her sons, so all the family was sort of the same mind** and I think with her talking to her sons about it too, **she didn't feel like she had made a bad decision** or anything like that, and when we saw her at the funeral she was actually very composed. I thought you know, I am sure **it helped having the conference .... //... I think it frees other people up to do what the person wants without them being the ultimate decision maker** (RN 23: Krys).*

### **Narrative 36: I surrender. Why prolong? No point!**

A sense of 'surrender' was one of the enhancing factors that promoted the positive experience with ACP. The residents who were interviewed attained peace of mind by surrendering themselves to the fact that they had had their time and it was time for them to go. It was pointless to linger when there was nothing that would bring the kind of life they wanted. They accepted that they were destined not to go against their fate by prolonging their life but to let nature take its course. For Morton who had lived his life fully with no regrets, it was simply practically and common sense to surrender himself for nature to take its course when there was no quality of life for him. He was able to submit himself through ACP by examining what quality of life meant to him and what he valued in life. For Jill and

Nadine, it was God who gave their life and who would take it away, hence they were not to disturb God's plan. Nadine said:

*Well **God must have set this up** as my life and he is the one who has made the decision and I have just got to go along with it. Yes, everything I have done is following what he has stipulated me to do. Look, your life is planned out for you Sarah, and there is nothing you can do about it. He decided to leave me with this problem and I have to accept it. I accept it and that is it. I don't worry about the what fors or the why fors or the anything fors. I don't worry about them. That is completely gone. Because I know that **I am not going to get better**. So what is the use trying to prolong something that is, I am only going to get worse. That is it. I have been associated with it for so long and accept the fact of what I have got and I know that **nothing can be done for me so why ... linger over it all the time**. It's just something that has happened. That is too bad (Res 9: Nadine).*

The families were strengthened by surrendering themselves to the fact that there was no point and future in letting their loved ones lingering on in a life that their loved ones would not have wanted. They searched hard for the reasons to resuscitate or transfer their loved ones to hospital but failed to justify doing so. Their decision to document 'no hospitalisation' and 'NFR' were, however, rationalised by the fact that it was meaningless to bring their loved ones back to life that would have not been wanted and to let them remain in pain and suffering. The families were provided with comfort and strength through ACP by seeking for the meaning and the objectives to be achieved for their loved ones. Taking part in ACP and documenting POT provided them with the relief that they surrendered their own desire to keep their loved ones alive in pain and suffering. Trish found that there was no future for her mum Nina. Theo found:

*I think ever since then she has had numerous bouts in hospital and the same question come up and we ... I guess we know what the answer is, the answer is just let her go if that's the way, that's the way God has decided so ... I think we, we all sort of generally agreed that it was better that she, well if it got to that point, that she was just let go that there wasn't any sort of invasive or any sort of ... aggressive treatment, exactly, because **we didn't think there was any point** and we felt that, you know, she would probably be in more pain. It wasn't worth doing and I think that, our family, all of us, we were in the same, we were in agreeance with that (FM 14: Theo).*

Freddy also found relief when he asked himself:

***... what is the point?** Yes. It comes down to **what's the point** when mum is suffering as she is, I mean, it is a pretty painful existence (FM 22: Freddy).*



Whilst the residents and families found comfort and relief through surrender, the RNs' comfort was enhanced by differentiating between euthanasia and ACDs. Although RNs found it difficult to explain how euthanasia was different from ACDs, the differences they perceived were that euthanasia would involve killing directly, whereas ACDs were meant to promote comfort and a pain-free situation through to death. They were adamant that they would not want to take part in euthanasia, as it was illegal. Heather said:

***It is not euthanasia so, that's definitely not. No, that doesn't enter my head. Well euthanasia is not Advance Care Planning. Euthanasia is completely separate. ... //... I am not for it at all. I wouldn't be involved in it and I don't believe in it. No, no. It is different. You are taking a life aren't you? You are taking a life with euthanasia or whatever you fancy to say. Advance Care Directives is still protecting a person's dignity and well-being and you are still looking after them as best you can. ... And you are certainly just keeping them comfortable as they progress from life to death (RN 5: Heather).***

**Narrative 37: The involvement of hospital care teams in ACP was the utmost endeavour and the ultimate hope was that I can revoke it**

It was sad, awful, and difficult for the family members who had to watch situations in which their loved ones were struggling with end-stage dementia. It led to broken hearts for the family members as they could not do anything to make the older person better. They suffered from the guilt of giving up on their loved ones by taking part in ACP and documenting POTs. The ultimate hope for the families who were devastated was that what they documented in the POTs was not a final death contract but open for negotiation and change by request or as needed. Unlike the residents themselves, who were satisfied with their decisions, the family members sought justification from the process and the health-care system that would represent their utmost endeavours. The involvement of the hospital care teams such as the palliative care team and PACS team in ACP was a sign of the utmost endeavour to minimise their guilt. It provided them with ultimate hope and reassurance that they could revoke it at any time.

Trish, who was very emotional during the interview and who was hard on herself about the decision she had made for her mother Nina, became hopeful that she could always change her decision when/if magic pills become available to cure her mother.

*I think about it (POT) all the time and it is constantly on my mind the whole time but I take the tack that I've made that and that's it. **It is always open for negotiation.** You know, if you know, six months down the track, if I feel that there is something else. Like if they produce this magic drug and said we give it to all the dementia patients, I would say 'Get the tube in there and feed her, keep her alive to get this drug in and let's see how it works'. I wouldn't hesitate but I don't think there's a future you know, there's no magic pill, there is no magic cure, there's no magic cure (FM 11: Trish).*

Laura, the niece of Mary who had never married, was reassured that she could change the POT for Mary any time if she wanted to and that she would still be the decision-maker to represent Mary's wishes. Doing ACP with Hanna was significant for Laura and her father, Mary's only surviving brother, as the ACP ensured that Mary would still receive care from the hospital.

*She (Hanna) came here, and she discussed all the implications of it and she's saying that **it doesn't have to be set in, in rock and concrete, it can change over time as the needs change.** So that is our intention, to be asked to review things at each ... //... Yes **we can change it at any time, that wasn't set in concrete,** and if you are not happy with it after a while, **we can always change it, we can always change it.** We can go down to the doctor, we can contact her (Hanna) again and she'd come out, and that gave us a level of certainty that we were still in charge of major decisions that have to be made. ... //... The thing that convinced us was that Hanna was saying that they can come in and **give her the same treatment as it would be in a hospital** but it would be in the familiar environment. That was the major thing. ... //... The other thing was that, dad thought that Hanna was part of the (hospital) team and that Hanna would be looking after her. He (Mary's brother) found out that **Hanna belonged to the hospital** (FM 19: Laura).*

Theo, who was very dedicated to the care of his sister Tia, was anxious that Tia would not receive any care from the hospital if he agreed in her POT not to send Tia to the hospital. Although he mentioned that he was happy and content with the care provided by the nursing-home staff, he was more comfortable and relieved to know that Tia would still get special care from the hospital in the facility as necessary.

*I mean at first, you know, before the discussion when I heard the hospital wanted to talk to us about that, about one that she was sort of treated in hospital or treated in the nursing-home... I thought **is the nursing home trying to give up on us,** you know, is this the way of having an extra bed available for somebody else because the nursing home, because **the hospital doesn't have, doesn't care any more.** Then when we had the discussion and when they talked to us and said 'Look there's not much more we can do' I sort of started to realise you know, that, I think **the hospital is sort of acting in my sister's best interest.** So, after I had a chat with them, **I felt more comfortable about it.** ... //... The thing that comforted me was that, you know, that*

*there was a special team that did that, they have a specialist team that comes in and that they take over her care, it wasn't just nursing-home staff, it was a special team (from the hospital) that came in and sort of specialised in that area, so I was comfortable from what they told me that (FM 14: Theo).*

The RNs ensured that the families needed to hold ultimate hope and they made the utmost endeavour to represent residents' wishes and needs. The families' experience with ACP was made more comfortable by involving Hanna, who was an expert from the hospital and who was an advocate for them, and by inviting the hospital care teams to the facility as participants in the ACP process. Rosa shared her experience as follows:

*I like to involve Hanna because then the families, I think, **feel more comfortable with, they think that we are in partnership with the hospital.** It seems to convey, 'Oh well they're not writing her (the resident) off, killing her off'. This is, by having multidisciplinary people attend it sort of conveys a ... that the **hospital really has done their best.** There is no more that they can do. If we say that without Hanna being here, I don't know that it would be as palatable. You know what I mean? ... //... We can say, we can say 'Well this is...' and we've had the hospice at times, this is a hospice, this is the, you know, Palliative Care Team from the Hospital, we are all involved rather than the nursing home being perceived as wanting to 'finish her off' because she is of no use any more. You know what I mean? ... //... Yes. So having someone from the hospital, the families and the resident may feel, they are assured, you know **'The hospital hasn't given up on me,** They still try to do good things for me'. So by doing or by documenting this (ACDs/POT) wouldn't necessarily mean 'I'm off'. And I think it is more comfortable for me because I am not the only one saying it. So it is kind of a team approach to support each other. Not the nursing home rejecting you, it is the doctor saying 'We've, we can't do any more for him'. Rather than not bring him back, we can't do any more, we can make him comfortable and give the nursing-home support, same thing as having it (ACDs) here with Hanna (RN 10: Rosa: DON 1).*

#### 5.1.2.2 Inhibiting factors

Transitions from positive to negative feelings and emotions occurred in the experiences of the residents, family members, and the RNs with ACP. The negative feelings and emotions that they experienced were sublimated to more positive and affirmative feelings about the end-of-life care decisions they made. The tensions, anxiety and guilt were released by a number of factors discussed above. However, the data also revealed that there were a few factors that made the participants resentful about their experience with ACP. The following Narratives describe the inhibiting factors (see Table 5 – 1).

**Narrative 38: We don't understand the readings, so talk to us.**

Laura was the person responsible for Mary with end-stage dementia. Laura documented a POT for Mary with help from Hanna. Laura felt difficulty and apprehension in the early stage of the ACP process because of her lack of understanding about what end-of-life care decision-making was about and what the consequences would be for Auntie Mary's care. She read a couple of books and leaflets about end-of-life care decision-making, however, it did not give her much by way of answers to her questions. Laura's experience with ACP at that stage was hindered by the written materials that resulted in her feelings and intellectual thirst to know being repressed.

*Well they (the books) were talking about intensive level of care, active level of care, maintenance level of care and sort of palliative care. So the descriptions were the differences. The difficulty that I had was with the, with the knowing when Mary was moving between the different stages because, we still think Mary has got a fair degree of functionality. Yes, she is giving stock answers and she is starting to say things that bear no relation to what we are talking about and **we don't know** whether that is part of the demise or whether it is also a function of her poor hearing. So that is a difficult stage and Suzie, the director of nursing, has said that it is part of the dementia stage but it is still, **it is still hard to come to grips with. The books I have read haven't been as descriptive of what I am to expect** (FM 19: Laura).*

It was not until Hanna explained and discussed with Laura the processes and implications of ACP that she understood where Mary was at with dementia, what ACP was and how it was going to affect Mary's care. Hanna came into her house and explained clearly the issues one by one, in terms that she understood what dementia was, how it would progress, where Mary was at, what was expected to happen, and what she could do to prevent some of the unwanted outcomes. Hanna's visits were continued until Laura was satisfied and comfortable with what she was doing in ACP.

Jill also experienced difficulties with written materials about end-of-life care decision-making. Jill, who believed herself to be a reasonably well-educated woman found it difficult to understand medical terms in the readings. Some of the examples in the readings did fail to create relevance to her situation. Jill did not see the points that others tried to make with their stories and how these could be applied to her situation until Hanna elaborated upon the stories and used these as a framework to discuss values, beliefs, worries and concerns in her life.

*I started reading the examples that were in that white book, I thought 'I don't think this is for me', like it is more for people who didn't have a clue what they were on about. I think there was too much also in there that, **the medical terminology and I am not a medical person**. Well there wasn't that much (that I understood), it was about pulmonary this and coronary that... it is all right if you know exactly. I mean I knew it was to do with the heart and everything but **I'm not an expert**, the specialists are. ... //... Some of the experiences with the people probably, I don't know. I thought '**Oh we are not in that position**' you know. And some of it was the families saying this, that and the other thing. I don't think we are in that position either ... I am not going to sit there and say 'If I can't go to golf a lot, it doesn't mean anything' you know because I, my, my wants are pretty simple I think. (Life is) not meant to be easy, so, **where to draw the line**. See even some of them said about recognising their friends and that. Well you don't recognise them now half the time (laugh). Oh, is that so and so (chuckling) (Res 18: Jill).*

Laura and Jill clearly demonstrated that simply leaving the written materials with them would not lead to documentation of ACDs/POT but would limit their experience with ACP as being complicated and difficult to handle. It was clearly identified that they wanted input into the decision-making process but needed to be encouraged and prompted with explanation and elaboration by an expert. Not surprisingly, it took time. It took time for Hanna to assess how the residents and the families thought about ACP, where they were at in the ACP process, what they knew, what they wanted to know, and what they needed to know. The residents and families were also required to take some time to reflect on their own thoughts, feelings, and concerns, which would then be discussed with Hanna. Hanna took time to identify how they lived their life and to help the residents and families transcend the limits of life at that time. Hanna emphasised how important it was to take time and how the whole process of ACP could be impeded by lack of time spent with residents and families.

*You know sort of, **you don't often have a lot of time**, the more time you spend doing it the better and you get more of a sense about that person and then you can say back to them, 'well my impression from what we have talked about, I get the sense that you're really, you make decisions this way or that way' or something like that. And they can agree or differ or they might think about that until the next meeting. A lot of Advanced Care Planning, like literature says it can take an hour and a half. **That would be a very low estimate for me, it is very rare**. I think I have had one person, one family that GP, myself, family met and we did the Plan of Treatment there and then one day, without any pre- or post- visits. **Everybody else has been hours and hours and that is a process in itself** but I think that then embeds, it is easier to embed that into ongoing care-providers to have that discussion, if they have that rapport (RN 25: Hanna: CNC).*

### Narrative 39: I am worried that I won't be left alone

Another inhibiting factor in the experience of ACP mentioned by the residents and RNs was that the end-of-life care wishes documented in ACDs or POT may not be followed for some reason.

Morton, as an independent and successful businessman, wanted to have control of his life even to the very end stage of his life in order to be himself. He was seriously concerned that his wishes expressed in ACDs, to refuse aggressive medical treatments that may prolong his life when he lost his capacity, might not be respected by health-care professionals. He criticised the acts of some family members as selfish, as they might want to prolong life to reduce their own feeling of guilt. Fortunately, his niece respected what he wanted and supported the decisions he made in his ACDs. However, he needed Hanna's input to make the transition from being worried to being reassured.

*A lot of people (families) at the moment may be prolonging the life because of their own issues like guilt or ... emotions. Everyone feels I don't want to let you go you know but **that's what they (families) want**. And that is very selfish. That's what worries me. And ... Maltreated ... **I am worried that I won't be left alone**. I am worried that there will be people fussing over me and all that sort of thing. Well I mean coming and poking at me and probing me. ... //... I know exactly how I want to die, as peacefully as possible and I think every person with any thinking processes working would feel the same way. No, I don't want to be writhing [sic] in agony and all that sort of thing. And I want to have all controls of my faculties. All control with everything. ... //... I thought she (Hanna) was a blessing, a blessing sent to me, especially as I got along so well with her so quickly. It has made me feel more confident in the way I am going and what will happen to me, yes it has. Very definitely, but **I hope it's true. I hope it all comes true**. (Res 21: Morton).*

### Narrative 40: 'Culture of do everything'

Morton's concern that his wish to be left alone at the end of life may not come true proved to be reasonable, as Suzie mentioned that the 'culture of do everything' is prevalent among doctors and families. She said:

*And then if you make an Advanced Care Directive and you've got it in writing and you are admitted to hospital, there are doctors there to save lives, what are they going to do? You know there is still that issue happening. **People are letting their wishes be known and yet they are still being kept alive**. So there is always something, it is not going to happen overnight (RN 24: Suzie: DON 3).*

The positive experience with ACP was challenged when some families demanded what the older person might consider as burdensome treatment. It was identified that the culture of 'do everything' was prominent underneath the decision to demand futile and aggressive treatment. It was noted that these family members did not make transition from guilt, sadness and discomfort to acceptance, relief, and comfort.

*Well I think a lot of, a lot of the referrals that come to me are because **families are so feral. Families are really difficult, they're seen as a problem, they are demanding** and, fault-finding and those sorts of things. (The staff say) well, I don't think this resident would want half of what we are doing but their **family is just demanding** all this stuff. ... //... Maybe that's how that family resolve that the person had a good death, because they can then say at the funeral, you know, 'Well they did everything they could'. ... //... if they are going to funerals I suppose, in hearing, family member saying 'Well, **we did everything we could**' and like 'oh he's a good son, he did everything for his mother'. Maybe that's what they live with, like well you've got to do everything you can because that's your job, **that's what's expected of you**. So it is almost like a community of society, expectation to do everything because if you don't do everything then you're just wimpy (RN 25: Hanna: CNC).*

#### Narrative 41: Culture of 'don't go there'

Another factor that was a hurdle in transition was the culture of 'don't go there'. The taboo latent within the culture 'don't go there' was obviously about the negative images about dying and death because death may occur or you may hurry up the dying process just by talking about it. Or the family could be in denial of the fact that their loved ones were at the end of life, that there were some decisions to be made, and that their loved ones could die in a manner not consistent with their wishes. Carla noted that some family members were left in discomfort, because:

*I just think that if, my opinion is **they are not discussed** early enough, they are not discussed, you know, everyone should have discussion here at the moment because who knows. I just think it is one of those things that aren't discussed enough, culturally, you know, I don't know. **We just don't want to go there** (RN 3: Carla).*

When Hanna was asked what made the family difficult in ACP she said, that in her experience:

*... **they don't want to know about it, they don't want to talk about it. Everyone is in denial**. Some families might feel that they are actually talking about a loved one, you know probably going to demise, families might feel a bit threatened or jinxed or might*

*be **in denial** and stuff. It is part of the process that we recommend people to think about who their decision maker is, it is the highest thing. Then there's [sic] people who haven't done any of that thinking. And let's face it that is the majority of people, it is human nature* (RN 25: Hanna: CNC).

#### **Narrative 42: Lack of family involvement in care**

Families who had the responsibility to make decisions for their loved ones reported that they experienced guilt. Interestingly, it was identified that the families who were not regularly involved in the care for their loved ones in the facility were less able to cope and accept the decisions made in POT, due to the greater level of guilt and regret that had originated from lack of commitment to the care. It was understandable that those who kept regular contact with the residents would have a better understanding of where their loved ones were at, the prognosis of the dementia and what they needed to be prepared for. Those who were not in regular contact suffered from greater hardship in their experience with ACP. Krys shared her experience as follows:

*So people like that just can't cope and I find often the people who can't cope the most are the **people who haven't been involved so much because the guilt thing is huge**. People who are very involved, visit regularly, spend long periods of time, they come to accept it more readily than someone who visits once a year* (RN 23: Krys).

It was clear that the residents, families, and the RNs who experienced that guilt, anger, discomfort and sadness in doing ACP became more acceptable, satisfying, content, and positive. The factors involved in the transition have been described and elaborated above. Their experiences after transition are presented in more detail below.

#### **5.1.3 Post-transitional status**

The words that were used to describe the experiences of residents, family members, and the RNs include acceptance, confidence, satisfaction, relief, comfort, happiness, reassurance and positive. A plethora of evidence was given by the participants to the researcher that represented these positive and affirmative experiences with ACP.

For the RNs, the experience with ACP and ACDs is focused on how the residents and family members felt and what they went through. RN Shelly mentioned that she



experienced acceptance through the residents and family members when ACDs were accepted by them.

*This is not an easy job first of all as you see, it is really a hard job but as I said this is not about me, make it easier for me or make it hard. If the residents really need palliative care involved, I **accept** that, you know, I don't care about the easy job or hard job, this is good for her and I **accept** that, that's it. Of course it is, you know, as you know it is really hard (to take care of Tia) and ... but this is our job, you know, we are here to take care of the people and that's it, it is the end of the story. We are not here to make us (nursing staff) comfortable or easier. This is my opinion, **we are just here to do a good job for the residents** (RN 15: Shelly).*

Theo was a 26-year-old man. His elder sister Tia has end stage MS. Tia was diagnosed with MS when she was 21 years old. She was looked after at home for 12 years by her boyfriend Kyle, whom she met at University when she was 20. She has had MS for 17 years now. Theo took over Tia's care while he was still working full-time, since Kyle married another woman five years ago. Theo fed, bathed, changed and groomed his sister by himself after work and with the help from home-care services during the day. Theo's mother found hard to come terms with Tia's condition and his father's sudden death by drowning seven years ago. Theo was a very beautiful, courageous, dedicated and mature person, with the intelligence and sensibility to articulate his experience with ACP with regard to his sister. He was asked a question about how it all started at the beginning of the interview. Once he started talking about how and where it all started, he only needed a couple of prompts to keep going. He talked, wept, smiled, despaired, contemplated, focused, sighed and took his time. On the other hand, he was assertive, confident and decisive in that he has done his best for his sister. He seemed to be determined to take this opportunity to talk about everything that he had in his mind. He was calm and composed at the end of the interview.

Theo has come a long way on the journey of being a main carer at such a young age. He experienced guilt, denial, sadness and a broken heart during the journey, but finally became comfortable with documenting the POT, the content of POT for his sister, the care given to his sister by the nursing staff in the facility, and the decisions he made.

*When I was asked, you know 'Can she be treated in the nursing home instead?' I was okay with that because I felt **comfortable** with the people who care for her (in the facility) and I know they will act in her best interest. So after the discussion we had a think about it... and my mum and I sort of agreed that's, that's the way we are going to go. ... //... So, I was, I was pretty **comfortable** with it (POT), my mum, she, I guess,*

*she didn't read the documentation but I think she, you know, she heard what the doctors said, I had the documentation so, you know, she listened to my opinion. I think we were both **comfortable** with, with what they told us and the documentation (POT). ... //... Yes, nothing you could do there. But I mean I don't know whether it is a unique situation or not but you know, we've had a year with the palliative care discussion, we've had almost a year now and nobody has made the decision to go back on that so, you know, in a way I am **comfortable** now that I think we have made the right decision (FM 14: Theo).*

Ray, who also suffered from guilt, a sense of the intricateness of the situation and sadness in limiting the care plan for his mother to palliative care, felt comfortable with the decision in the end. Freddy and his brother Scott wrote end-of-life care statements for their mother Connelly, who had end stage dementia. His brother and he thought that making decisions for his mother with regard to future medical treatment and having the decisions documented in the statement was a positive experience, as it has given them comfort.

The residents, family members and the RNs have all experienced happiness with ACP and ACD/POT, but in a different sense. Tess was happy because she respected Vincent's end-of-life care wishes through ACDs. Jill and Morton were happy because they had made the decisions for themselves through ACP and the decision was fully supported by their significant family members. There was a consistent response that the majority of the RNs felt happy for the residents, as they would not be subjected to any unwanted medical interventions but be respected and their wishes upheld. The RNs felt happy for the family members in that the decisions had been made and documented by involving everyone, so that one sole member in the family would not be blamed for the death of the older person. Krys said:

*I think they (family members) are **happy** because I think they feel **comfortable** that the decision has been made; it is hard for people to make these decisions no matter how ill the person is. So the decision has been made and I think they sort of breathe a sigh of **relief** that that decision, it is sort of the **weight is off the shoulders** now, nobody ever feels that they are the one, you know, sticking the knife in. So everybody ... people have all talked about it and all agreed, so I think they feel **comfortable** in it. There would be no point in doing it if the family wasn't happy about it. The ones we have done so far, that I can remember, there haven't been any negative. We will never do, we will never make a protocol that the family isn't happy with. So, there's never been a bad outcome, they've all been quite **happy**, quite **comfortable** and ... //... I am **happy** that they (the residents) won't be subjected to anything that isn't appropriate for them. They won't be sent over to the hospital when they don't need to go, that, like the young one, she won't have to endure that all the time. I wish with Mr MF he'd done something like that. That would be great if they all had it (ACDs/POT) (RN 23: Krys).*

Morton could not say enough how pleased he was that he had documented his wishes in ACDs. He described his experience with Hanna from the initial visit to the last one as a positive and sensible act. Morton did not have any negative feelings about doing ACDs and felt reassured that he would be looked after the way he wanted to be at the end of his life unlike his sister who had a horrific death.

*I didn't know that they could do that (documenting ACDs) and I think it's a really sensible thing rather than live on life support for 10 years. ... //... Yes, I would think it is a very good idea and I am **pleased** I am doing it. I think yes everything so far has been certainly not negative and as far as I can feel **positive**, very **positive**. So yes, I am more than **pleased** to do what I can to help with the directive ... //... It (ACP) certainly has made an effect on me. It is more **reassuring** to begin with. You know, I feel, yes, that is all there is to it. It takes a load off one's mind. When you live alone and you have got lots of time to think about yourself. Not that I think about myself a great deal because I don't, but the time you do spend thinking about yourself it can be very negative but with this (ACP) it seems to have a more **positive effect**. You seem to be heading in the right direction more than sort of wandering around looking for an answer. And also the word again **reassuring**, that is one, to be **reassured** and you know that you are going to be looked after and well treated beyond that ... //... Well I think it probably, the **reassurance**, the peace of mind. You know what is going to happen to you, you know you are going to be looked after. Surely anybody with any common sense, if they had a choice would choose the benefit rather than the drag down. That is what I would say (Res 21: Morton).*

The residents, family members, and the RNs all experienced a sense of relief when ACDs or POT were completed and in place. Nadine, who was only able to drink milk and tea with a couple of biscuits a day, was relieved. As she expressed herself, what she was not happy about in the past and what she wanted to be done in her care in the future was resolved through the ACP processes. Ray was sad and felt a great level of guilt in the beginning of the ACP process. However, he was finally relieved with the decisions he had made. Ray was relieved to ensure that his mother Lily would not be locked in a life she would not have wanted. The RNs and the family members who documented ACDs/POT were relieved in that they had had opportunities to talk through issues within the family group and with the nurses, and they came to conclusions to which everyone agreed.

*... a **relief** that I have got it all off my chest. And now I know that it's there for them to see in black and white. Because I could go into hospital any time and be told that I had to have surgery and I wouldn't be able to convince them that I shouldn't. (Res 9: Nadine)*

*I was concerned but in a way I was also **relieved** that the decision had been made. When that decision was made, yes. ... //... Oh yeah it was sad of course, yes. Yes it was sad but, actually once I made the decision, in a way I felt **relieved** (FM 16: Ray).*

*I think, I think there is a sense of **relief** that a decision has been made and that they have been able to come to a satisfactory conclusion within the family circle that they are happy with, and that they feel this is probably what that person would have wanted anyway. I think there is a sense of **relief** that a decision has been made* (RN 24: Suzie: DON 3).

The experiences of the residents, family members, and the RNs with ACP were also expressed as satisfying and without regrets. Theo, the young man who was the substitute decision-maker for his sister with end-stage MS, felt guilt, difficulty and a broken heart, but his family and he were satisfied with the care provided to Tia in the facility since the documentation of POT, and they would not regret the decisions they had made.

*I think it is the right decision we've made and the thing is, this decision was made I don't think this year but last year. So it has been over six months now, almost a year basically since this (POT) was made. I **don't think that any of us have regretted** it. If we had we would have changed it by now. You know, I think that's ... and in a way Tia, I think Tia has had more bouts of pneumonia or infections. She's been treated here each of those times and you know, she seems to recover from it. So, I think we are really comfortable with the type of care that the nursing home provides in case she does have an infection so, you know. I think that we've got no, I **don't think we have any regrets** about our decision* (FM 14: Theo).

Tess, who was the substitute decision-maker for Vincent with end-stage heart failure and MND, although she was not related to him at all, felt a great level of burdensome and responsibility earlier but was also satisfied that his wishes were respected and with the way he died.

*Everything, I put him in a good home, I followed all his wishes. I never upset him, not once. I respected him. So **no regrets**, I have done everything that he wanted me to until the end after he died, he wanted a Greek Orthodox service in the church, which cost a lot of money, but I have to do it. It is his wishes. So all the way, all the way. I can live with myself, my conscious is clear. You know what I mean? It gives (me) great **satisfaction** knowing that and **happiness** you know what I mean?* (FM 8: Tess).

### **In summary**

The experiences of residents, family members, and RNs with the ACP process in RACFs have been described in Section One. The participants experienced various negative feelings and emotions such as guilt, difficult, discomfort, broken hearts, awfulness, stupidity, cruelty, burden, anger, abuse, confrontation and resentment. These feelings and emotions

led to a positive transition resulting in acceptance, confidence, satisfaction, relief, comfort, surrender, happiness, reassurance, being positive, and being pleased by enhancing factors. There also existed inhibiting factors that interrupted the positive transition.

The participants' experience with ACP was projected as an image through eight narratives collected using secondary analysis through the CIT, as described in Chapter 3. The residents believed their essence of being was enhanced through ACP, as it allowed them to be who they had always been. They expressed high levels of satisfaction (transcendence) in the life that they had, and therefore did not want to waste society's limited resources by hanging onto life any longer than they wanted to. The residents and families made the decisions by themselves. However, their willingness to execute the right to decide needed to be understood and promoted in the social context, given that they made decisions in consultation with other family members, and that they wanted these confirmed by health-care professionals as the right decisions.

RNs experienced satisfaction and comfort with the decisions made in ACDs and POT by differentiating ACP from euthanasia, whilst the residents and families gained relief by 'surrendering', as there was no future. For some family members it was important to have hospital care teams involved in ACP, as it was the utmost endeavour from them. They were also comforted by the fact that they could revoke directives at any time. An important indication for the nurses from residents and families was that the residents and families would not be left on their own with written materials to develop directives, as they had expressed difficulty in understanding the concept of ACP, the prognosis of dementia, and the consequences of having or not having treatments. It required a well-qualified expert and sufficient time to explore how the person lived life, how s/he had made decisions in her/his life, what the person valued in life, and what the person would or would not tolerate at the end of life.

It was clear from residents and families that the fear of the wishes not being followed up because of the culture of 'do everything' negatively impacted upon their experiences. It was also revealed that death and dying were taboo topics among the participants, which resulted in a lack of discussion about and specificity in ACP and ACDs/POT.

The nurses, including the RNs, the managers, and the CNC, were heavily involved in the implementation, outcomes, and experiences of ACP in RACFs. In the next section, the findings relating to the scope of nursing practice in ACP in RACFs are presented.

## **5. 2 The scope of nursing practice in ACP**

The ACP program was implemented as a pilot project on the NSW site. The scope that is the range, breadth and depth of associated nursing functions related to episodes of care in the context of ACPs has never been explored, developed or even discussed formally by nurses involved in ACP or within the wider nursing profession. Therefore, one of the aims of the study was to determine the extent of nursing participation, and the scope and nature of opportunities for nurses in the ACP process and documentation of ACDs. The purpose of Section 5.2 is to present the findings on ‘how the scope of nursing practice was perceived by the CNC and the RNs in ACP in RACFs’.

After exploring the implementation process of ACP, the outcomes of ACP, and the experience with ACP by the participants, it became apparent that the expert nurse and the RNs in the facilities had to work with and through a number of sub-elements in the ACP process. They made significant contributions to the experience of residents and family members in end-of-life care decision-making. Not surprisingly, the findings in the implementation process, outcomes and experiences of ACP clearly projected a distinctive image about the scope and nature of nursing practice for past, current, and future ACPs.

The behaviours that determine the scope of nursing practice were collected during the interviews and observations. The CNC and the RNs were asked during the interviews what they perceived their roles and functions were in relation to ACP, and how they felt about what they were doing in ACP. The data collected during the observation period added a different set of information to describe the range, breadth and depth within the scope of nursing practice in ACP. Following the analysis of observation and interview data in relation to the scope of nursing practice in ACP, it became evident that recurring functions were identified and that the overall activities of the CNC and the RNs in RACFs were expressed in a similar way to Andersen’s (1978, 1991) models.

Andersen, an Australian nurse theorist (1978, 1991), undertook her initial research with 576 graduating student nurses in order to (among other goals)

- undertake an analysis of the activity of nursing
- relate graduating students' performance on key aspects of the activity to the desired performance
- seek explanation of the performance.

The project consisted of two parts, an analysis of practice and an evaluation of student performance, and the five key questions used to analyse practice were:

- What is the nature of nursing?
- What is/are the goal(s) to which the practice is addressed?
- What is the nature of the person who is the recipient and/or the initiator of care?
- What is the nature of the interaction between the initiator and recipient of care?
- What is the nature of the context within which the practice occurs?

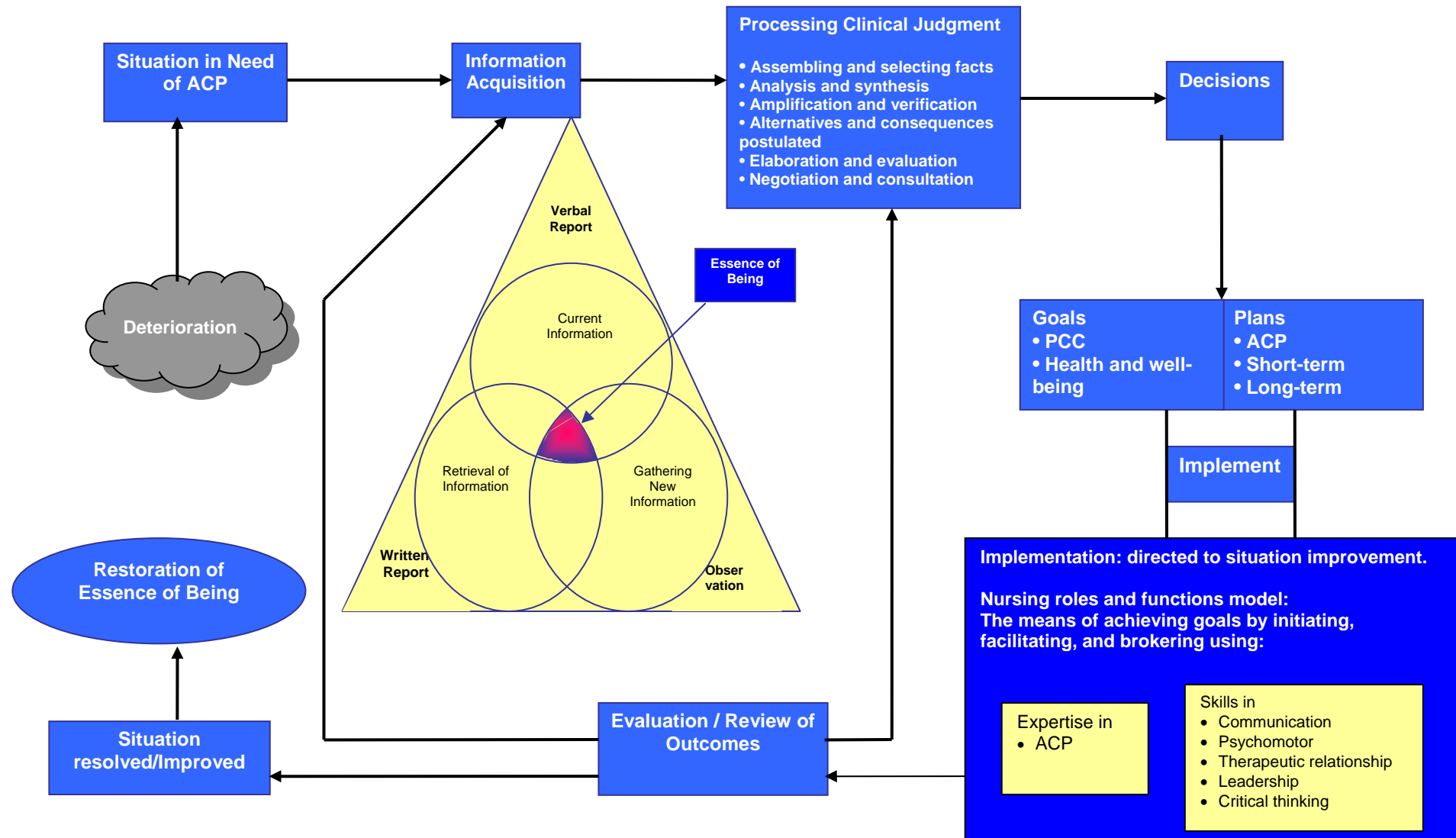
She developed a series of models from the project; one was the 'Nursing activity model' (Andersen, 1978), and another was the 'Intervention: Nursing roles and functions model' (Andersen, 1991) as a classification system, which was subsequently further developed in other research and curriculum development activities (Andersen, 1991; McMillan et al., 2001). The 'Nursing activity model' described the components which constituted 'the nursing activity' that involved a stimulus, an input and an output. She conceptualised the relationships between components and their underlying behaviours as that the activity was more than the sum of its parts. The nursing activity was considered as successful when each of the components utilised a range of concepts, behaviours, skills and appropriate attitudes. Andersen was keen to elaborate further on the concept of 'intervention' within the output component of the nursing activity. She was able to elicit common functions, roles, role relationships, goals and modes of intervention in the 'Intervention: Nursing roles and functions model'. The models developed were initially tested in 'general' medical and surgical nursing settings. The validity of the models was examined and approved after testing the models in other nursing areas, including psychiatric and developmental disability nursing.

The two models developed by Andersen have contributed to the data analysis in the current study. The Nursing Brokerage Model A in ACP (Figure 5 – 2) is the product of the analysis of the ACP process developed from an application of her models to the scrutiny of actual practice in the context of the present study. Nursing Brokerage Model A represents the process of enquiry as it applies to and shapes nursing interventions where there is a resident care situation to be improved. The model represents the elements of nursing activity undertaken by the CNC, the expert in ACP. It also reveals how the CNC brokered ACP by careful consideration of residents' situations where there was a need or request for ACP. The nursing activity in terms of any resident care situation 'needing improvement' is the starting point in an ongoing process that leads to a comprehensive set of clinical judgements in response to the resident's needs. The model clearly demonstrated that the CNC acted as an agent who explored all the options that residents and family members might have and who drew out agreements from everyone involved in the care of an older person on end-of-life care wishes in directives or plans. The CNC used her clinical judgement to process the information she collected through verbal and written report as well as her observation. The Nursing Brokerage Model B in ACP (Figure 5 – 3) elaborates how information was acquired by the CNC.

The CNC functioned as an intermediary to achieve the best options for everyone, using her expertise in ACP and a number of skills in communication, psychomotor, therapeutic relationships, leadership, and critical thinking. The CNC needed to work collaboratively with the managers and RNs in the facilities to achieve the goals which were PCC and the maintenance of the health and well-being of the persons via ACPs. Therefore, it was in the element of 'Implementation: Directed to situation improvement' that the image of roles, functions, and modes of interventions performed by the CNC, the managers, and RNs emerged in detail. An attempt was made to elaborate the image in 'Nursing Roles and Functions Model in ACP'. The researcher will describe the elements of the 'Nursing Roles and Functions Model in ACP', as depicted in Figure 5 – 4.

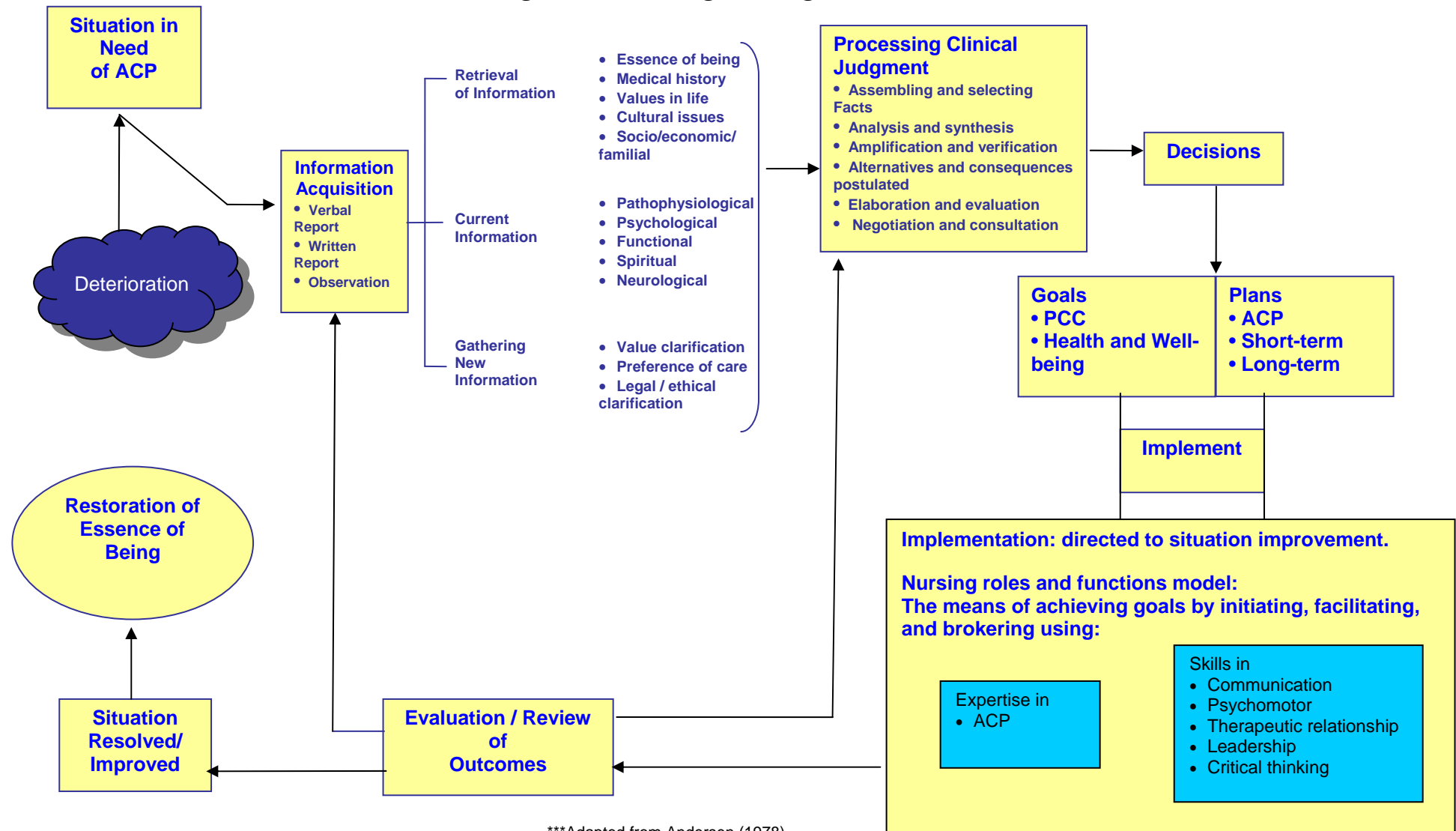


Figure 5 – 2. Nursing Brokerage Model A in ACP



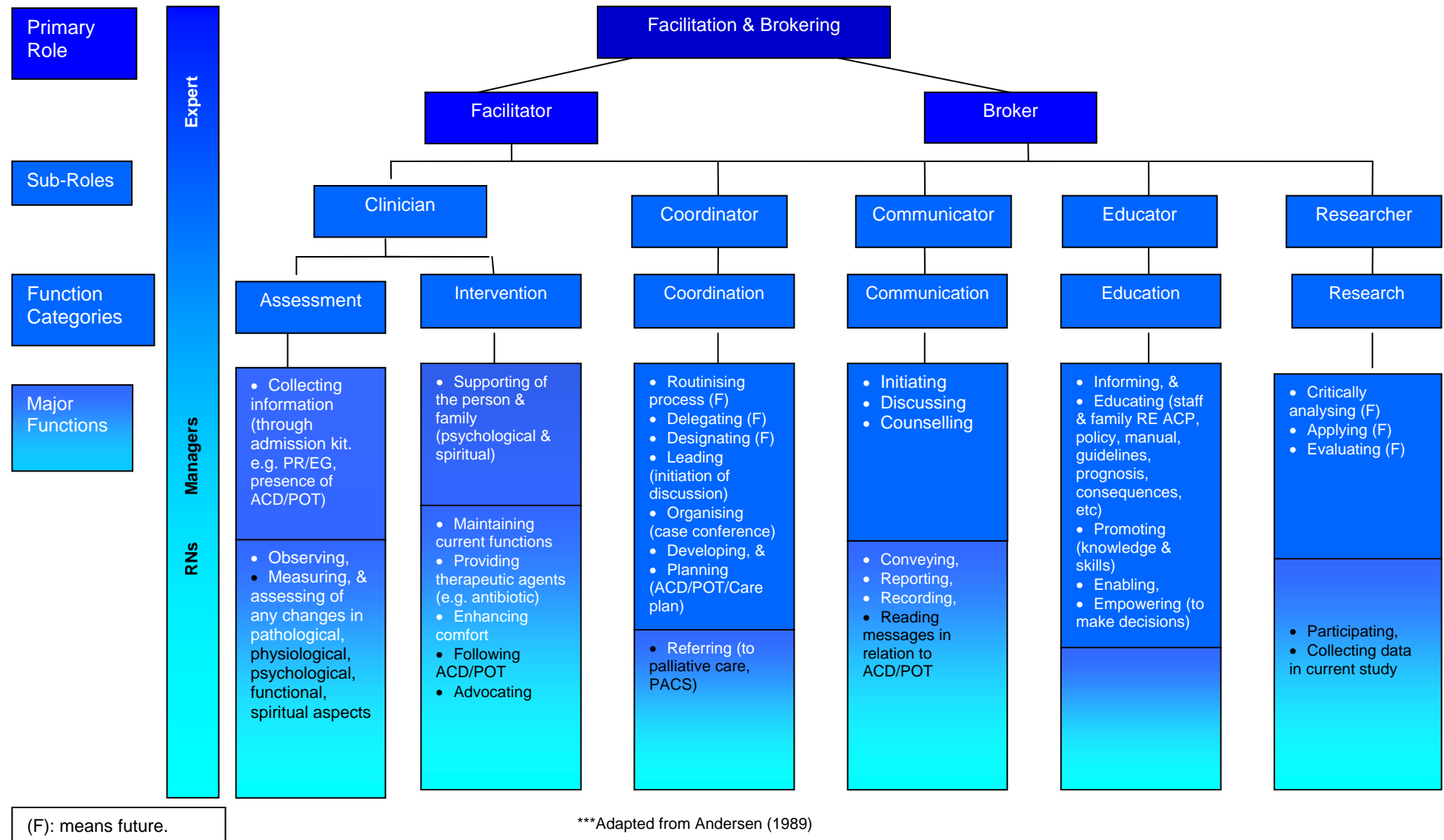
\*\*\*Adapted from Andersen (1978)

Figure 5 – 3. Nursing Brokerage Model B in ACP



\*\*\* Adapted from Andersen (1978)

Figure 5 – 4. Nursing Roles and Functions Model in ACP



Nurses' roles and functions are classified in this context of practice as part of a system which articulates two primary roles, those of 'facilitator', and 'broker'. The primary roles are then extended to five sub-roles, those of 'clinician', 'coordinator', 'communicator', 'educator' and 'researcher'. Six function categories are classified from those sub-roles and major functions describe what each category entails.

To more fully describe the scope of nursing practice, the researcher applied another level of analysis to the data collected through the use of the CIT (Flanagan, 1954) and linked the elements reflected in the Nursing Brokerage Model and the Nursing Roles and Functions Model into the excerpts. The researcher has selected the CIT to capture critical observations of a situation (**S**) relevant to the phenomenon, the action (**A**) taken to resolve a problem/situation and the result(s) or reflective outcomes (**O**) emanating from the actions taken. Therefore, Situation – Action – Outcome (SAO) was used as a framework for presenting the CIT analysis of the scope of nursing practice in ACP in RACFs. Situations are underlined, actions taken are *italicised*, and outcomes are presented in **bold** in the excerpts.

In conjunction with the above, the researcher presents a series of narratives reflecting the key issues in ACP to draw themes that capture and reveal the relationship between nursing interventions and outcomes of nursing care for residents and families in ACP. Four exemplars are combinations of unique nursing interventions (see Appendix 19) and juxtapose *best* and *limited* practice by nurses involved in the ACP process and its outcomes. Each narrative represents a theme or themes drawn from the thematic content analysis. In the following, the roles and functions of the CNC and the RNs are elaborated.

### 5.2.1 The CNC

The findings of the research have clearly revealed that the CNC, the managers (DONs) and the RNs assume different roles and functions in the processes of ACP. These ACP processes heavily relied on the expert nurse (the CNC) to facilitate the whole process. The expert nurse's primary roles were that of a **facilitator** who set up the ACP process, who helped the managers and the RNs in the facilities to take up the ACP, and made suggestions and recommendations on solving the problems or difficulties that nurses were faced with in this care situation. She was also a **broker** who mediated between people

involved, providing a bridge between the different health-care teams, and filling gaps found in ACP processes.

The expert nurse as a facilitator and a broker embraced the sub-roles of clinician, coordinator, communicator and educator. She foresaw her role as a researcher developing from the current one. The major functions she performed under these sub-roles were assessment, intervention, coordination, communication, education and being a participant in a research project. She was one of the researchers involved in the initial pilot project centred on ACP, a key informant in the present study, and her practice was reliant on evidence-based practice.

#### **Narrative 43: ACP is a process that promotes health and well-being**

It is important to note that what the CNC believed underpinned her role in ACP. She made it clear that ACP was not a ‘product for sale’ to those who could afford it but a ‘process’ that would promote health and well-being for everyone. It was her role to set up the processes that entailed honest, cautious and mutually beneficial conversations.

Excerpts	Function categories	Major functions
<p>(RN 25: Hanna: CNC)</p> <p>I never really thought that we were the decision-makers as health workers, but it is more looking at that process and using it as an advantage to get the best care and treatment for residents or patients, and to use it ... //... <b>we weren't selling a product, it was more the process.</b></p> <p><u>It would be good if, what about when the document is not available for transfer and what do you do about if they want too much treatment and what do you do if they don't want enough treatment and they are trying to bump themselves off, you know, by default, by not having active treatment'. So there is all that sort of cautionary... I mean caution is a good thing because if you do it cautiously and address it robustly, then you're probably going to have a better product in the long run than everyone going 'Oh this is fantastic, let's just do it, tick it all off' and suddenly all the warts come out (laugh). You know, you can do a great document but it's not worth the paper it is written on because the process is pretty bad.</u></p> <p><i>I'll come out and see them and then I will ring you back</i></p>	<p><u>Situation</u></p> <p><i>Action:</i></p>	<p>Collecting,</p>

<p>and see what I've found, see if you're on the same pace sort of thing. Talk about what we can and can't provide or try then at that point, try and draw out what their understanding of what the patient would be thinking and saying. <u>That's sort of a hard process for them as well too.</u> Because often they don't know what they are <u>thinking or saying.</u> Then I might start talking about what sorts of treatment and what they do or don't, what the benefits and burdens might be.</p>	<p>Assessment, Communication, Education, Intervention. <u>Situation</u> Action: Communication, Education.</p>	<p>Discussing, Counselling, Teaching, Supporting.</p> <p>Discussing, Teaching.</p>
---	---	--

**Narrative 44: It is hard to think about what I will be and what I will do when I am not myself**

The expert nurse's facilitative role and functions of assessor and communicator were highlighted in that it was hard for the general population to think about whom they will become and what sort of treatment they would or would not want when they were no longer themselves. In other words, ACP was not a simply task of ticking off boxes for what they would or would not want in future when they were no a longer competent persons by law. ACP required a high level of abstract thinking to foresee the benefit and harm resulting from the desired treatment and to comprehend the outcomes of having or not having certain treatments.

[illegible]

<p>themselves in a position where they won't be able to think this through. And maybe that's too hard an ask of people. But maybe um the directive itself ... Like some, yeah I just ... It is almost like <u>well when you are at that point, what do you want, one or two have sort of said 'Well I'll make that decision when I am there' and they are clearly missing the point that 'Well you won't be able to make that decision then, because you won't be able to think'. So I think our thinking process is really close to our heart. Our thinking processes drive who we are and what we are and all meaning in our life and those don't touch on that, they just think it is about their bowels and bladder (laugh). And maybe it is too hard a concept. It is a really hard place for them to get to, to think about that time. It is a very dark place to go. 'Who will I be when I am not me, who will I be when I can't think for myself'? Or, 'Do I have to decide now who will I be in the future'? Who will I be, you know, in my current future self versus my non-compos future self? ... // ... That's why we say to everybody 'This is what will happen when your time comes'. If you don't like that process you might want to do an Advanced Care Directive to help them or provide a guideline or provide some advice about how to make those decisions.</u></p>	<p><u>Situation</u></p> <p><i>Action: Education, Coordination, Communication.</i></p>	<p>Teaching, Informing, Developing, Planning, Discussing.</p>
--	---	---

The expert nurse has taken a unique approach to helping residents and family members think about choosing or refusing future treatment options. She believed that people would make decisions based on who they have been and how they lived their life. Therefore, she explored the values of the person from their perspective or that of persons responsible if they were not capable. They were given an opportunity to express who they have been, what the important things were in their life, and how they have made decisions in the past. The images of her roles in assessment, intervention, communication and education were prominent and demonstrated why she was the expert in this process, as none of the other nurse participants performed to this level within the roles and functions appropriate to the ACP process.

Excerpts	Function categories	Major functions
<p>(RN 25: Hanna: CNC) Probably just going through the value sorts of things and challenging them. Yes, <u>I started off asking her, she'd already got the form but she was blind so she couldn't read it. So I read it to her, that's where she needed my help. Um, she had very clear ideas, ... I guess what was naturally instinctive for me was to ask things like, 'Well tell me about your life and when you</u></p>	<p><u>Situation</u></p> <p><i>Action: Assessment,</i></p>	<p>Collecting,</p>

<p>grew up and who was important in your life' and probably just wanted to see whether she was depressed or whether there was [sic] other things happening there, or if she had made any attempt on her life and then I found yes she had and oh no, tried to commit suicide when you're 40. Um ... perhaps ... and that turned out that she was quite stable, she had a bit of a wild younger life sort of thing. She wanted to live and she wanted to do good things and be productive and all that, but she recognised that she had a point where, you know, in life where she might have a stroke and stuff. <b>So it was good for her to talk through with her neurologist about her risk factors were too,</b> because maybe she was sort of dwelling on something or something happened. And to talk to her a bit about the reality, you know when she gets sick. You know the ambulance would probably come and knock on the hospital because no one wants you to be in a position where you, because doctors can't treat you, you are going to end up in the very position you don't want to be in. <b>So that was interesting for her purposes but in asking her about her life and growing up and her family and stuff, she said 'You are asking some really interesting questions, why do you want to know?' She was really quite surprised ...about the stuff I was asking. But it is almost like you need to know all that background to sort of shape other things or just be aware of factors in their life. ... //... Well I think in going through a little bit of chronology in their life, where they have been, where they are at, what shaped their decisions as they have along, and that's what will help ... // ... what was [sic] the milestones in your life and how did you approach those milestones, like are you an impulsive person, do you just go 'that's it, that's the answer' or do you go and seek wise counsel or three wise men or look it up on the internet to get all the information or do you just believe what you hear, do you think about...'</b> You know sort of, you don't often have a lot of time, the more time you spend doing it the better. ...//... A lot of Advanced Care Planning, like literature says it can take an hour and a half. That would be a very low estimate for me, it is very rare ... //... <b>The past experience is probably a good predictor of, you know, future performance, therefore, future decisions. It will be consistent with the way you have lived your life. ... // ... she was surprised I think. I think she just thought I was going to come and do the directive with her. And then finished. Yes, like I am just here to get this written and get out of there. But you can write a document but it's, you want it, if you are going to help someone do it you want it to be a reasonable process.</b></p>	<p><i>Communication, Intervention.</i></p> <p><b>Outcome</b></p> <p><i>Action:</i> <i>Assessment, Education, Communication, Intervention.</i></p> <p><b>Outcome</b></p> <p><i>Action:</i> <i>Assessment, Communication, Intervention.</i></p> <p><b>Outcome</b></p>	<p>Discussing, Supporting.</p> <p>Collecting, Informing, Promoting, Enabling, Discussing, Supporting.</p> <p>Collecting, Discussing, Supporting.</p>
--	---	--



**Narrative 45: Initially, not many residents were competent to document ACDs and not many families wanted to know more about ACP**

When the expert nurse commenced the ACP program, she noted that there were not many residents who were competent to make decisions for themselves and there were not many residents who had a substitute decision-maker identified to make decisions for them. The expert nurse realised that there should be something in the process for those incompetent residents and for the person responsible to help in decision-making.

Excerpts	Function categories	Major functions
(RN 25: Hanna: CNC) <u>Because they, the patients (residents) themselves weren't able to make decisions and we needed to have, we needed to look at 'well what is the process if someone can't make decisions for themselves, what do we do now, what is in place'? We need to work with what's in place already and so in place was already the Guardianship Act to actually go through that. ... // ... I guess it was due from (a) that there wasn't, ..... what I was hearing from the nursing homes wasn't about patients wanting to do a directive, it was more that there are so many patients here who can't make decisions ... //... About the year 2010 there will be all these people with dementia with worn-out brains and they won't be able to think and they won't be able to, they won't be in a position and it just seemed that I was seeing all of those people here and now in 2001, not 2010. It was like a sea of people with worn-out brains and what on earth are we doing, what are we doing? Not that it is right or wrong but what are we trying to achieve here, how do we make those decisions if they can't tell us what they want? So sure, if we get them earlier, they might be able to tell us what's important. We can provide care that's consistent with that.</u>	<p><u>Situation</u></p> <p><i>Action: Communication, Education.</i></p> <p><u>Situation</u></p> <p><i>Action: Communication.</i></p> <p><b>Outcome</b></p>	<p>Discussing, Initiating, Informing, Teaching.</p> <p>Initiating, Discussing.</p>

The expert nurse was not able to proceed in setting up a process for those incompetent residents and for the person responsible without the permission and participation of RACFs. She organised a meeting with the managers to identify those who might be interested in implementing ACP processes in their RACFs. The expert nurse facilitated the managers' agreement to participate in the ACP program to develop forms to identify persons responsible for the residents who were currently incapable of making decisions and who did not have a person responsible nominated. The managers were also given help

from the expert nurse to set up the process through the use of a form at the time of admission to identify the person responsible for those incompetent residents. Having a substitute decision-maker identified in ACP meant that the decisions at the end of life would be made not by the doctors or nursing staff but by the family member(s) appointed, those who knew what the older person would want, and allowing nursing staff to follow their directives.

[illegible]

The expert nurse also needed to develop POT forms for those cognitively impaired residents to have a person(s) responsible identified and to document end-of-life treatment

options, as the Guardianship Tribunal made it clear, when she referred the matter to them, that a person(s) responsible could not make ACDs for an incompetent resident.

Excerpts	Function categories	Major functions
(RN 25: Hanna: CNC) <u>the Guardianship Tribunal when we saw them, sort of said 'Oh well a proxy can't really do this directive'. So we called it something different (POT), we said yes this person is clearly incapable and they are not getting better and they are not going to ... we try to allow them, give them every opportunity for them to have that input but it is not going to happen. We are being realistic here, we are also looking at what we can, we want to promote health and well-being, we want to allow for reversible illness, we want to see what we can do for them ... // ... So it is very ... um, it was a positive thing, going to the Guardianship Tribunal, it helped us to see a way through and how it could work, to make a bit of a framework as an approach to test it out a bit.</u>	<u>Situation</u>  <i>Action:</i> <i>Coordination.</i>       <b>Outcome</b>	Developing.

Once there was a process to identify or appoint a person(s) responsible, the expert nurse provided the residents, GPs, managers, and family members with brochures developed by her to follow up those who were interested in taking further action in ACP. At this stage, the expert nurse started to get referrals from the managers in RACFs and the GPs.

Excerpts	Function categories	Major functions
(RN 25: Hanna: CNC) <u>To then say 'Do you have an Advanced Care Directive, does the resident have one, do you want more information?'</u> <i>Either they (the managers) could go through it or they could get someone (the expert nurse), there is someone at the hospital they can ring up, she can come and talk to you about this. So get the question out there, there are a few brochures, we (I) developed, on Advanced Care Directives and Advanced Care Planning, so they just ring us (me) up or the nursing home or GP might ring and say 'I think I have got a referral for you'.</i>	<u>Situation</u>  <i>Action:</i> <i>Coordination,</i> <i>Communication,</i> <i>Education.</i>  <b>Outcome</b>	Developing, Organising, Discussing, Informing, Promoting.

### Narrative 46: Education was one of the most important functions in ACP processes

It is important to note how the expert nurse interpreted the concept of ACP and what she did to apply ACP into RACFs. She realised that the ACP would be new to old people, families, and even nurses and they would need to know what it was and how it would help them. Therefore, when the expert nurse set up the ACP process in the area, education was the main part of her role. She approached the residential facilities to offer in-service education sessions to the residents, families, and the nursing staff, especially the RNs. She also extended her invitation of the education sessions to the GPs who visited those facilities. The content of her education sessions were mainly about consent, a substitute decision-maker, and the *Guardianship Act* (as recommended by the Steering Committee).

Excerpts	Function categories	Major functions
(RN 25: Hanna: CNC) So it was still a big learning curve for me as well too, as to how it could apply. The only advice I had was to go out and teach nursing-home staff about consent and the <i>Guardianship Act</i> and that seems to have been good worthwhile advice ... // ... <u>If a patient, in a directive, if they refuse treatment, they are not all refusing treatment, they might be wanting certain treatment. If they are refusing a treatment then that would constitute as an objection to treatment within the Guardianship Act.</u> So it is important to know the basis for the <i>Guardianship Act</i> ... // ... Yes, so in service for the nursing staff then um, invited facilities if they wanted to be part of the project. We (I) then talked to GPs who visited that facility, so we (I) did a couple of talks to GPs at different facilities in that area. We (I) just talked about the project, and that was pretty well received. We (I) only had about seven or eight GPs but they were probably the ones that visit numerous facilities. <b>So they were aware and said ‘Yes that’s fine’. Some GPs weren’t positive at all. Some were downright you know, just really thought it was euthanasia dressed up as something else,</b> and I think that is a common theme with members of the general public, RNs, GPs. It is just people’s perception if you are talking about death and you are trying to plan a good one, that it’s got to be euthanasia but it’s not. <u>No it is an act to actually ... and it is sort of reminding people of our obligation to promote health and well-being.</u> It is sort of the higher order of things. So, so there was the training to the nursing homes via in service. We had GPs, relatives meetings, go and talk at relatives’	<u>Situation</u>	Teaching.
	Action: Education.	
	Outcome	Informing, Teaching, Promoting.
	<u>Situation</u>  Action: Education.	

<p><i>meetings, that's an ongoing role as are the RNs in services and things ... // ... I think raising awareness of it ... If we raised awareness of what we can do, we can look proactively um, approaches, we can look proactively at the care we are providing. Look at in a sort of an objective framework of minimising negative, enhancing positive. Um, and maybe it doesn't become about the directive, maybe it becomes about the discussion and getting that on to a regular sort of agenda ... // ... it is a bit like rehab, it is all about enablement, as is dementia care. It is trying to encourage independence and people to do things for themselves and stuff. So it is trying to bring out all the best of people and minimise the worst.</i></p>	<p><b>Outcome</b></p> <p><i>Action: Education.</i></p> <p><b>Outcome</b></p>	<p>Enabling.</p>
---	--	------------------

Her role as an educator included training of the medical and nursing staff in the A & E Department in the hospital, as it was crucial that they were aware of ACP to follow the older person's end-of-life care wishes documented in ACDs or the POT documented by the person responsible through the ACP process.

Excerpts	Function categories	Major functions
<p>(RN 25: Hanna: CNC)</p> <p><u>So then we had a number of Advanced Care Directives or Plans of Treatment that were documented and then okay, you could have those nice little documents but then when their resident gets sick, what actually happens ... // ... Um, so if they do come in, we (I) did a training session for Emergency Department staff and registrars and that as well, the consultants there. So they were really positive in the whole ... they are certainly supportive of the notion and they know it happens, so the paperwork ... they go 'Okay, that looks good, that looks clear'. If they (residents) come in and they've got a reversible thing and want PACS, they (the doctors at A &amp; E) will do their first IV line, we (they) will put in the IV antibiotic, we (they) will start that and we (they) will try and get them (residents) back to the nursing home as soon as we can. That's the aim here, and they are familiar that that is the aim of treatment basically, that's what we are trying to achieve.</u></p>	<p><u>Situation</u></p> <p><i>Action: Education.</i></p> <p><b>Outcome</b></p> <p><b>Outcome</b></p>	<p>Informing, Teaching.</p>

### 5.2.2 DONs and RNs

The managers' roles and functions in the ACP process were highlighted in assessment by collecting information from residents and families, in coordination by organising the case conferences, in communication by initiating the ACP discussion at admission and counselling as necessary, in education by informing and promoting the knowledge and skills of the nursing staff, and in research as participants in the available research projects.

The RNs' roles and functions in ACP processes in the current situation were quite limited, even minimal, according to their own admissions. They were involved in all six function categories, however, the major functions they performed were (i) observing, measuring, and assessing pain and discomfort, (ii) enhancing comfort, and following written ACDs/POT, (iii) referring the problems to other health-care teams such as the PACS and palliative care team, (iv) conveying expressed messages from residents and families to the managers, (v) advocating for residents and families, and (vi) participating in research the project.

**Narrative 47: Everyone is passing the buck with no understanding of each other's roles.**

As mentioned previously, there are a number of groups of people involved in ACP processes. Among them, RNs and the managers in the RACFs undertook vital functions in assessment, intervention, coordination and communication in ACP. The expert CNC facilitated the whole ACP process and believed that she empowered the RNs and the managers to take part in ACP process. However, it was interesting to note what they expected of each other. The data collected during observation and interviews suggest that the RNs expected the managers and the GPs to take an active role in initiating and discussing the residents' care, whilst the managers believed that the RNs were in a good position to initiate the discussion with the families. Both the managers and the RNs reported that the CNC was the person who took the whole process over, and who completed the documentation of ACDs/POT once they made a referral to the CNC, whilst the CNC assumed that they were doing ACP by themselves within the facilities.

Excerpts	Function categories	Major functions
<p>(RN 10: Rosa: DON 1)</p> <p><u>I think they (the RNs) need to be more aware that this (ACP) is an option the families have, am, and while I hopefully will talk with most families I don't always. And quite often they (the RNs) develop relationships with the family and they are in a position to offer that. And I think that that's why they need to be more educated so they are aware that they can offer this.</u></p>	<p><u>Situation</u>  <i>Action:</i>  <i>Communication.</i></p> <p><u>Situation</u>  <i>Action:</i>  <i>Education.</i></p>	<p>Initiating, Discussing.</p> <p>Teaching, Promoting, Enabling.</p>
<p>(RN 3: Carla)</p> <p><u>I think, I believe a lot of the nurses have an expectation or belief that the doctors have that discussion. But the doctors don't always have that discussion, so then, we are at the coal face of the family saying, what is going to happen to mum or dad? And we say, what do the doctors say, what did they say, and they say nothing.</u></p>	<p><u>Situation</u></p>	
<p>(RN 26: Katrina)</p> <p>I guess (ACP) would be in the domain of the DON or DDON. You know when you are ringing up for admission placement, if I was a DON, that's what I would be doing, I'd be really, really focusing on Advanced Care Directives. But <u>I mean I am not in that position. I am not in a senior management position ... // ... Well I think it, I think management is quite, I think they can do it really.</u> I mean it is not a real big nursing home and there's a DON and a DDON and an administration person. So I think it needs to, <u>I think possibly where it needs to come from is from either the DON or the DDON because they are here all the time and they're doing the admissions. I mean you know, it makes sense that the person, or the first line of contact, they may not be doing the admissions but they are the first line of contact. So I think possibly that would be the place to start.</u></p>	<p>Situation</p> <p>Situation</p>	
<p>(RN 24: Suzie: DON 3)</p> <p>... // ... sister Mary does (ACP), I don't think, I don't know, to be honest I don't know how comfortable she is with that and that's something I would have to find out from her but I know that she is doing it also. I know that the staff, the senior staff (RNs) are also asking questions of families. ... // ... <u>It is not a dictatorial thing that has to happen. It is not like, 'Here's the form which one do you tick'. Here's the form, fill it out (laugh). It is not that at all. It is just being able to provide the information and I guess it is to get people thinking and to support the families or the residents through ... They can't make the decision for them, they just can't, so it is just providing information and support.</u></p>	<p><u>Situation</u>  <i>Action:</i>  <i>Education</i>  <i>Intervention.</i></p> <p><u>Situation</u>  <i>Action:</i>  <i>Education</i>  <i>Intervention.</i></p>	<p>Informing Supporting.</p> <p>Informing Supporting.</p>

<p>(RN 5: Heather)</p> <p><u>I have been in the last little while when I do admissions, I usually do try to discuss it. And I, to see if they have made any plans ... // ... I would ring Hanna (the CNC) to get her out to visit. <b>We keep out of it after that. It is between them ... // ... It is not up to me to make any legal documentation about it but I would refer them then to Hanna.</b> Other people ... well, you can't really initiate it, someone has to come to you. They have been in a home for some time and it's up to the relatives really to approach. Maybe they would approach the GP. Sometimes they do that.</u></p>	<p>Situation</p> <p><i>Action:</i> <i>Communication,</i> <i>Coordination.</i></p> <p><b>Outcome</b></p>	<p>Discussing Referring.</p>
<p>(RN 7: Wilma: DON 2)</p> <p><u>Yes, I make referral to Hanna, yes. I am not always. Sometimes the staff (the RNs) out in the ward say like Heather or somebody else will say oh they (the residents) said, they said, they don't want to go back to hospital, they don't want any more treatment or they don't. And I will say, okay we need to get Hanna involved ... // ... Yes, because I don't have the time to actually spend with the family to go through all the issues and to, to look at are they depressed, are they ... I don't have the time to do that properly and so that is why it is useful having Hanna as a resource to do that.</u></p>	<p>Situation</p> <p><i>Action:</i> <i>Coordination.</i></p> <p><u>Situation</u></p> <p><i>Action:</i> <i>Coordination.</i></p>	<p>Referring.</p> <p>Referring.</p>
<p>(RN 25: Hanna: CNC)</p> <p><u>I can't tell them this (ACP) is okay, they're got to feel like this is the right thing to do ... // ... And maybe a few more have been developed within facilities, <b>people just doing it themselves through you know, their planning processes and admission stuff.</b> They are getting a higher turnover so there are more people coming through, well they can introduce it (ACP) ... // ... I am not out in those nursing homes every day and therefore, often the nursing homes will say 'Oh I've got someone for you to see' because you are there, but if you are not there then they don't think to tell you about them. So, that's all right, but um, I'd like to think they are picking it up. <u>I was sort of worried at one point, I thought 'well maybe even though I am busy and I'm not out in the nursing homes, perhaps they (the nursing homes) are not doing it (ACP), they are just thinking the project is over or something or the other'.</u> But then the patients, <i>I was asking emergency department staff where a lot of nursing home patients coming inappropriately and they said no they weren't. <b>So it led me to believe that nursing homes were doing it, they were getting more of a handle on it and stuff, and a few that I have spoken to just anecdotally sort of were feeling like they were doing it and they knew I was here. They don't ring me up saying 'Oh I've been doing this Advanced Care Plan, I have had this terrible problem' like and maybe they're just discussing, they were just getting comfortable with having</b></i></u></p>	<p><b>Outcome</b></p> <p><u>Situation</u></p> <p><i>Action:</i> <i>Coordination.</i></p> <p><u>Situation</u></p> <p><i>Action:</i> <i>Communication.</i></p> <p><b>Outcome</b></p>	<p>Leading, Organising.</p> <p>Discussing.</p>



<b>discussions with families.</b>		
-----------------------------------	--	--

As evidenced above, it seems that the RNs, the managers, and the CNC involved in ACP processes had unspoken and unaccepted expectations of each other. It was clear that there was a misunderstanding and an absence of communication on how each individual was performing her/his roles and functions in ACP processes. It is important to note that they shifted and imposed responsibilities on each other to some extent without discussion. It was assumed that each individual should understand her/his roles and maximise her/his functional level without any framework or model of care available to follow at that time.

The CNC believed that the staff members at RACFs were comfortable and confident with ACPs and she did not have to get involved in ACPs in RACFs at all times. The managers took some part in their roles in ACPs but demanded that RNs take a more active role. RNs anticipated that the managers in the facility should have been more involved in ACP by initiating the discussion with family members on admission, without knowing that the managers had already integrated this as a formal process in admission forms. The managers would initiate the discussion on admission and inform the family members about the availability of ACPs, however, they believed that they did not have the time to facilitate a resident or a family member to complete the ACD or POT. It was the CNC who they thought would take the ultimate responsibility in helping the older person and the family member document ACDs or POT in ACP. The following comment made by an RN represents what was expected of Hanna and how much she was appreciated for her role in ACP.

*I think she (Hanna) has been **like a white light** that has come in and is having conversations with residents and getting things documented. So that that's helping us know at the end of the day, what level of care or support or things people need and when they want a change somewhere. So it has made our job a little bit easier particularly with some difficult residents that ... we just haven't been sure of so, ideally it would be great if she saw everybody. That would be the ideal, but I know ... I don't sort of foresee whose role it is but, I think somebody as special and sensitive as her (Hanna) needs to be starting the ball rolling. **We need to clone her** (RN 3: Carla).*

Whilst the above comment highlighted the importance and extent of the CNC's influence on RACFs, the roles and functions performed by the RNs in ACP were fairly limited and minimal, as further described in the next Narrative.

### Narrative 48: The RNs' roles in ACP were minimal and limited

The RNs in RACFs were not significantly involved in ACP processes. Their roles and functions were not clearly defined and quite limited to symptom management and to alerting the managers to initiate ACP discussion with the residents or family members who expressed 'no-hospitalisation' or 'NFR'. As clinicians RNs observed and assessed the pain and comfort levels of residents, and provided nursing interventions that included maintaining current functions, providing therapeutic agents, enhancing comfort, preserving dignity, advocating, and following written ACDs/POT. They were not involved in organising a case conference and their role was limited to referring residents who showed deterioration in physical health to PACS or the palliative care team in the hospital. RNs made written notes in nursing progress documentation for any events that happened. However, as far as ACP is concerned, they simply conveyed messages or hints from residents or family members to the manager to contact the expert CNC for ACP.

Excerpts	Function categories	Major functions
<p>(RN 15: Shelly)  <u>when they just decided, not to send Tia to the hospital, I was not there and that's it, they just discussed it with the mother, you know, they just, it's a better way.... we keep her here ...</u></p> <p>(RN 10: Rosa: DON 1)  <b>They (the RNs)'re not usually involved in the discussion, they just get, they get just told what the situation is and what the plan is</b> <u>because they haven't got time to leave the floor.</u></p> <p>(RN 6: Rita)  <b>So it is not my role, it wasn't my role or job to ring or investigate or go further about Advance Care Directives. It hasn't been so far.</b></p> <p>(RN 13: Katie)  <u>I have never been to a family meeting ... // ... I read what has happened, yes, I read it in the progress notes, yes, and handover and you read the progress notes and you are reading what has happened and follow what they suggest, you know, follow it through. Yes.</u></p> <p>(RN 4: Donna)  ... one thing is we (RNs) do, for example, this is within the policy, we have to make sure, um, for example, people who are in pain, like behaviour people,</p>	<p><u>Situation</u></p> <p><b>Outcome</b></p> <p><b>Outcome</b></p> <p><u>Situation</u></p> <p><b>Outcome</b></p> <p><u>Situation</u></p> <p><i>Action: Communication, Intervention.</i></p>	<p>Reading, Following ACD/POT.</p>

<p>behaviour problem people, <u>we have to make sure they haven't got infection for a start, urinary tract infection or chest infection.</u> <i>Then we rule out that they don't have pain, right, then we can manage them easily. That's my role to be able to manage their behaviours, make sure they are pain-free, free from infection. Things like that.</i></p>	<p><u>Situation</u> <i>Action:</i> <i>Assessment</i> <i>Intervention.</i></p>	<p>Assessing, Providing therapeutic agents, Enhancing comfort.</p>
<p>(RN 2: Mia) <i>If they need morphine, put them on morphine. We assess them if they respond good to morphine or whatever analgesia. <u>If they are still in pain, we document it or we increase it ... Ah ... so that's why it is not only resident that is important, the family is important too because we want them to be happy to see their, you know their family here, that they are comfortable because they are at the end of the life, for everybody, losing someone is very hard. So we have to have both sides not only the residents, always.... Anyway we always inform them of the residents' condition so ... we spend more time with them when they (the family) can't. We never do force-feeding with them if they stop eating. We want them comfortable as much as we can.</u></i></p>	<p><i>Action:</i> <i>Assessment,</i> <i>Intervention,</i> <i>Communication.</i></p>	<p>Providing therapeutic agents, Reporting.</p>
<p><u>They (residents) stop eating and express their wishes to die ... // ... Yes, yes always we document it in their progress note and care plan. We always do ... // ... Yes, that resident wants to go, so try not to force-feed, don't argue and just observe not to have pain.</u></p>	<p><i>Communication,</i> <i>Intervention.</i></p>	<p>Reporting, Advocating, Enhancing comfort.</p>
<p><i>So in that situation my role as an RN is to contact the palliative care team and raise their issues to the DON <b>so the family conference can be organised</b> ... // ... Yes, and sometimes ... we have to, <u>because this palliative care team from the hospital, they have to be notified if that medication is responding to the resident so they come and review.</u></i></p>	<p><u>Situation</u> <i>Action:</i> <i>Communication,</i> <i>Assessment.</i></p>	<p>Conveying message, Reporting, Observing.</p>
<p><i>It depends on RN because we are the ones, not the doctors. <u>We see the residents every day and the progress every day. If they are getting worse, so, of course we call the palliative care. It is not only they are dying. Sometimes they are not dying, but they are in pain, arthritis, osteoarthritis, shoulder pain, leg pain, something like this, and then what you do for them is not enough. And you want something stronger to make them comfortable so you give them morphine.</u></i></p>	<p><i>Action:</i> <i>Intervention,</i> <i>Communication.</i> <u>Situation</u></p>	<p>Referring, Conveying message.</p>
<p><i>Every time the condition gets worse, next of kin has to be notified. <u>So if (a) resident is on palliative care and then suddenly breathless, very short of breath or temperature or pneumonia or like this, because in case they die in the next minute, we have to notify them to come and stay with their father or mum. And I say your mum or your father is like that, so if you want to stay</u></i></p>	<p><u>Situation</u>  <i>Action:</i> <i>Intervention.</i>  <u>Situation</u>  <i>Action:</i> <i>Communication.</i> <u>Situation</u></p>	<p>Providing therapeutic agent, Enhancing comfort.  Reporting.</p>

<p><u>with them, and they say, no, no, no, send them to the hospital, send them to the hospital.</u> And then ... we have to send them to the hospital. <b>And sometimes they get better and they come back ... // ... So obviously we have to listen to them, they are family, it's very important. Always we have to listen to them.</b></p>	<p>Action: Coordination, Intervention. <b>Outcome</b></p>	<p>Referring, Advocating.</p>
<p><u>I observe the resident. If I see the continuing resident is in pain, the crying of pain, doesn't sleep at night so there is something wrong somewhere. That is why I always ring the doctor and ask do you want me to ring the palliative care?' because what we do for her is not responsive and the doctors say, yes ring the palliative care. They come and assess the resident.</u></p>	<p>Action: Assessment. <u>Situation</u> Action: Coordination. <u>Situation</u> <b>Outcome</b></p>	<p>Observing.  Referring.</p>
<p>Everywhere, we document the case conference and we document the care plan and we document the progress notes, there are three places and then on the handover sheets we always tell them, you know, <b>at the case conference, this resident is for palliative care.</b></p>	<p>Action: Communication.  <b>Outcome</b></p>	<p>Recording.</p>
<p>(RN 3: Carla) I take it as a privilege working in aged care now. I couldn't have foreseen myself years ago doing this but <b>you actually are an advocate.</b> You are saying what they can't say. Or if someone has done something inappropriate you are their voice often. So, <u>sometimes just, you know, what they look, or you are privy to the discussions of the family members saying, look I don't know what to do, when is enough enough? And they say things that are ... in their heart often. And we hear that, they don't always express that to the doctors or whoever is running the facility ... // ... You can see people in aged care that are passionate about it (ACP) and there are who aren't. I think if they are passionate about looking after the whole person and making their end-of-life experiences as comfortable as possible then advocating that ... // ... Talked to them. And really enable the person involved to express.</u></p>	<p><b>Outcome</b> Action: Intervention.  <u>Situation</u>    Action: Education.</p>	<p>Advocating.    Enabling, Empowering.</p>

The data collected suggest that the reasons for the RNs not being seriously involved in ACP process include, first of all, that the RNs have no time to leave the floor. They would need the manager's permission to leave the floor.

Excerpts	Function categories	Major functions
<p>(RN 23: Krys)</p> <p><u>I think probably because the case conferences take so long and the RN's day is quite busy and um, we would prefer. I mean we have talked about it, we talk about it to the RNs on the floor, before it happens as well, saying this is what we are hoping to achieve from this (case conference), or this is what the family wants (to) achieve from this. But then they can't spare an hour or hour and half off the floor, no and we would prefer that they stay there and do their medication, documentation, wounds management etcetera, look after the residents there and then we will, we tell them afterwards or show them. Individually we will show them what the protocol is and what's in place, what the family want. Then they are more comfortable with it.</u> Sometimes we do, they might come in for five minutes or ten minutes just to say whatever, if they want to say anything but <b>usually they are quite happy that it is all been sorted out, they have got this thing, this document that tells them what they can do, what they don't do.</b> So yeah, as managers we have so much time (laugh).</p>	<p><u>Situation</u></p> <p><i>Action:</i> <i>Communication,</i> <i>Coordination.</i></p> <p><u>Situation</u></p> <p><i>Action:</i> <i>Communication.</i></p> <p><b>Outcome</b></p> <p><b>Outcome</b></p>	<p>Discussing, Leading.</p> <p>Discussing.</p>
<p>(RN 3: Carla)</p> <p><u>She (DON) was having discussions with Hanna, and um, to see how they could move forward on this (ACP) and maybe they are. It's just something that we (RNs) don't regularly know what the updates are unless we ask or they are documented in the notes.</u></p>	<p><u>Situation</u></p>	
<p>(RN 26: Katrina)</p> <p>If I was asked to do it I would definitely, but <b>I wouldn't at the moment. I wouldn't until I was given the all clear,</b> you know. <i>I, no, I would always defer to um DON or ADON, probably DON ... // ...</i> Oh just, well <u>I am not management, um I'm er... probably because I am not full time um ...</u> If I was working here full time I would possibly say you know 'Do you...' We are, 43 residents is very heavy work load for an RN, so there really isn't a lot of time for anything extra but if an area was made ... Using a scenario. Okay I am talking to the DON and I am saying, you know let's say, 'Okay what do you think, we start promoting things about Advanced Care Directives?' and She said 'Oh that sounds like a good idea' or yeah, let's say it is a positive thing and she says 'That sounds like a good idea'. Then I might say to her 'Well would you like me to become the Advanced Care Directive co-ordinator?' I would be happy, <u>I would do that but I would need, it would need to be sort of slotted somewhere outside of the role that I am doing already, yeah.</u></p>	<p><b>Outcome</b></p> <p><i>Action:</i> <i>Coordination.</i></p> <p><u>Situation</u></p> <p><u>Situation</u></p>	<p>Referring.</p>

<p>(RN 3: Carla)</p> <p><b>I am not privy to the family conferences of what goes on there, I haven't been involved.</b> So I am assuming ... so ... in an ideal world the family conferences would be fantastic. <b>But I am not sure how often and how regular that (family conference) happens</b> ... // ... <u>I think if time permitted in our schedules, it would be good to be an advocate for the relative or for the resident, particularly when, yeah, you are with them a bit more often.</u> Yeah, very much. Yeah.</p>	<p>Outcome</p> <p>Outcome Situation</p>	
---	---	--

Secondly, some RNs believed that ACP was not part of the nurses' roles but rather the doctor's role. Katie was adamant that:

*As I said, this (ACDs) is not my decision, **this is doctor's decision** and he knows his patient better than me, you know. He knows, because they are a doctor, they know the problem. Yes. ... // ... I don't want to get really involved with that problem. Not me, no. ... // ... Of course this is my job, involving in the care is a different story because this is my job, I have to do it, but involving in treatment. I, I have no right you know, to make a decision about the treatment **because I am not a doctor, this is the doctor's job.** That's why they are doctors, and we are nurses. No (RN 13: Katie).*

Shelly agreed with Katie and said:

*I am not talking to the family about the treatment or ... this is ... I never do such a thing. I'm just talking about my job, about what can I do for the, you know for your mum or dad. I never dare to just talk about their, you know. If they want to know about their treatment, **they can just talk to the doctor, talk to the doctor. Treatment is not my business, treatment is doctor's business.** If they want to know about the treatment I can give a phone number, doctor's phone number, they can just call and you know discuss this. (Do) Not discuss this (ACD) with me, I am not entitled to ... just do the, those things ... the only things I know, my job is just (to) look after residents and, just make sure they are comfortable, they are free of pain, they get medication, they just get the care. This is my job ... // ... I don't mind really, you know, of course it is an extra job but I don't care, you know, as long as she is really comfortable I don't care. This is our job, we are just working for them ... // ... involving, just involving, for the care, not involving for the treatment ... // ... No I don't want to be involved in treatment (RN 15: Shelly).*

**Narrative 49: Routinising ACP and having one designated person is the way to go**

Whilst the RNs participated in ACP processes with the expectation of being more active without a clear understanding of what their roles were and how they should function, the managers' roles and functions were highlighted as taking part in the ACP program and initiating discussions with residents and family members on admission with regard to end-of-life care options. The CNC expected the managers to stand alone and run ACP processes within the facilities, and the RNs imposed more responsibility on them to put processes in place. In the absence of any framework or an example of models of care in ACP, the scope of nursing practice at the managerial level did focus mostly on initiating discussions, organising case conferences, counselling, informing, and empowering.

Excerpts	Function categories	Major functions
<p>(RN 4: Donna)</p> <p><u>Maybe they just want to cling on. They feel guilty. And then, if you like am, usually, the DON has done that, talk to them, reassure them again and they settle down and see reason, at (the) last minute, they feel guilty, they cannot see reason. They think that there is hope but in actual fact there is no hope. So at that time we have to tell them, step by step re-reasoned and then they see sense again.</u></p> <p><i>... organise case conference, organise these people to come, all these things, organise family members, time, discuss with the director of nursing, what time is suitable, things like that.</i></p>	<p><u>Situation</u>  <i>Action:</i>  <i>Communication.</i>  <u>Situation</u>  <i>Action:</i>  <i>Education,</i>  <i>Communication.</i>  <b>Outcome</b></p> <p><i>Action:</i>  <i>Coordination,</i></p>	<p>Counselling.</p> <p>Informing, Counselling.</p> <p>Organising.</p>
<p>(RN 23: Krys)</p> <p><u>usually when it reaches that stage the family is also halfway there, it just needs guidance to show them the direction to see, to let them see clearly. Lay all the cards on the table and tell them one by one, you know, what is right and what is wrong and the doctor's point of view, what they can offer and then everybody comes to an agreement and the best care for the person involved.</u></p>	<p><u>Situation</u>  <i>Action:</i>  <i>Education,</i>  <i>Communication.</i>  <b>Outcome</b></p>	<p>Informing, Teaching, Discussing.</p>
<p>(RN 7: Wilma: DON 2)</p> <p><i>My role is probably to make the families aware that they can do this and that it is all right for them to think about these issues and to, and to make decisions for the person they love. I think sometimes they are so</i></p>	<p><i>Action:</i>  <i>Education.</i>  <u>Situation</u></p>	<p>Informing, Empowering.</p>

<p><u>overcome by coming into a nursing home and everything else, you know, it's all too much and then they are scared. A lot of them feel that if they say, I don't want any more treatment, that people are going to look at them badly. So I think it's good to be able to tell them this is okay, you can say that. You don't have to just prolong someone's life just to look good ... // ... So I guess also am, I see my role as flagging, hey we need to get this done.</u></p>	<p><i>Action:</i> <i>Education,</i> <i>Communication.</i></p>	<p>Informing, Empowering, Initiating.</p>
<p>(RN 24: Suzie: DON 3) <i>I think it is information giving, I think it is a supporting role, um probably those two at the moment. Information and supporting. It's not, it's not um ... they don't have a role of demanding that it happens. I just think it is information and supporting the persons involved, at the moment. That's all you can ask of them.</i></p>	<p><i>Action:</i> <i>Education,</i> <i>Communication.</i></p>	<p>Informing, Supporting.</p>
<p>(RN 10: Rosa: DON 1) <i>I try to allay their fears by saying that, you know, what we really want is if there looks like, there has been another major insight or this or that, at what level do you want us to treat them conservatively or go everything. You know, but if you go everything, you know, what the consequences of that could be for them. So you are actually painting a picture for them and that <b>they can stipulate that if mum has a heart attack I want her to be comfortable.</b></i></p>	<p><i>Action:</i> <i>Education,</i> <i>Communication.</i>  <b>Outcome</b></p>	<p>Informing, Empowering, Enabling, Supporting.</p>

Although the managers' participation in ACP focuses on informing, promoting, and supporting the residents, family members, and the RNs in ACP processes, the extent of their scope of practice was not expanded any further. In contrast to the RNs' request for the managers to be more directive and liable, the managers and the CNC recommended that the ACP process should be infiltrated and practised by the nursing staff on the floor. Establishing a 'routine' was suggested by the participants for the ACP processes to work better and the appointment of one designated person as a champion in ACP whom other staff refer and who provides easy access and availability as necessary within the facilities. Hanna shared her experience as follows:

*Seeing it in Boston was good because they, they do it every time they have a Care Planning session. Like every time they basically have a case review, it is like 'Oh now we're with the family, we have talked about the Advanced [sic] Care Directive before and you have had any thoughts, do you want us to make any changes, okay we'll re-endorse that, review that again in three or six months'. So it is just on the menu, on the menu, on the agenda all the time, so it doesn't go away and it is not because people are harassing families, it is just that it is part of the process. So if we have got a part of*



process then I think it is more likely to stay **as part of a routine** rather than if it is all new and a bit too precious and too difficult and too hard and too prone to problems ... // ... I think if you can sort of mesh it **as part of your routine**, that's probably a better thing, but the reality of that is that we've got an overwhelmed, tired, overstressed workforce, so they seem to say it is just a whole other thing to do. But it doesn't need to be that if it is part, if you have got a process set up for regular review and things, in place. So you need some back up, I think ... // ... It would be nice but it is not a priority and maybe when they get their more regular staff or management turns around or you know they might have just one nurse that decides they want to do it and takes it on and adopts it **as like a champion** sort of thing, then that would be a good thing too (RN 25: Hanna: CNC).

Wilma also suggested the same idea as Hanna. She said:

I don't actually complete this (Care Plan form) any more. This is what Heather does. The Care Plan is done ... from probably, she starts doing it about a week after admission and fills it in until about ... week seven when it is completed and she would probably get this bit of the information from the front sheet. But how it should work is that, when we, **what we would be doing is having at week 6 (of admission) having a conference with the family and then we should be able to raise that**. Because on the conference record it actually talks about Advance Care Planning. ...//... I haven't got it (routinising family conference at week 6) organised yet. It's time, it's just, it's, but it is more than time. It is **putting it into, into somebody's work, like making it part of somebody's job**. This is what we do. And I think **until it becomes part of what we do, it won't happen. And to make that happen, somebody has to drive it, you have to follow up, you have to keep following up until it becomes a habit**. This is what we do and that's why it hasn't happened ... // ... Yes, **one designated person**. Yeah, I think somebody needs to take it on as a project. Anytime anything has been successful it's because one person has driven it and they have been given, you know this is your project and it works much better that way ... // ... So when you have got one person who takes it on as a project it happens. It works much better because everybody always expects everybody else to do it. So ... And I mean, I guess, if that one person takes it on board you might find that the other RNs will then be able to refer them, if they can't refer them to me they can refer them to say Carla or to Rita as the person who can then communicate with Hanna and do all of that (RN 7: Wilma: DON 2).

The above suggestion requires motivation, education and participation from the nursing staff. Whether or not the nurses are willing to or feel obliged to expand their scope of practice remains questionable, but Katrina and Carla have provided some insight. Katrina said:

**I probably should be asking more questions.** Ask if people ... start asking more questions you know. Ask if people have them (ACDs). Go and see the DON and ask if that person has an Advanced [sic] Care Directive and if not, ask what ... I will always be guided by what she says because she's the DON and it is her decisions, you know, but possibly just say 'Do they have an Advanced [sic] Care Directive, do they know about it, do they want information, are we pursuing that line of thinking.' You know and

*if the DON says 'Well yes, we can pursue that line of thinking.' I would then say 'Would you like me to ask them about it?' and I would ask them, if I got the okay from her, you know. I would never ever just go ahead and do it off my own bat, never, because she's the DON and I respect that position. And I can make suggestions but I would never. If she said 'No I don't want you to pursue it' I wouldn't. I don't think she would though, I think she's probably just so busy thinking of other stuff, so yes. So **I could be more proactive about it**, yes (RN 26: Katrina).*

Carla said:

*I am comfortable with it but I am aware that it needs to grow. **I need to be more actively doing things** (RN 3: Carla).*

### Narrative 50: We are not research-active yet

The scope of nursing practice in ACP was revealed by analysing and developing a relevant nursing roles and functions model in this situation and context of practice. One of the sub-roles mentioned by the participant as necessary for the model was 'research'. The data collected during the observations and interviews suggests that research activity in the ACP process was not active and not taken into consideration by the participants at this stage. The extent and level of participation in research activity with regard to ACP at the time of the data-collection period among the RNs, the managers, and the CNC were not considered as extensive, by their own admission. Hanna reported:

*... // ... didn't really have any sort of, satisfaction survey for families or anything around that or nursing-home staff, it was more just a verbal feedback on how it all went. Generally everybody thought it went really well, but **I mean that's anecdotal** (RN 25: Hanna: CNC).*

The CNC was asked to establish outcome measures for the ACP project.

*So you've got your current group of residents, plus your prospective people coming in. So you sort of had two processes. Two processes for that. I recall this because one of my first sort of management meetings they said could I put together a process for **how I might have some outcome measures for the project**, so I had a number of in-services, a number of GPs, a number of this and that. Numbers of people wanting to be involved in Advanced [sic] Care Planning discussions and those sorts of things. What sort of documentation they already had. Some had a 'not for resus' order in the nursing home. Some had things like 'don't transfer to hospital'. So it was trying to make the process a bit more simple and easier. (RN 25: Hanna: CNC)*

Given that the concept of ACP itself was new and often controversial, and the implementation of ACP in RACFs was a pilot project, one can only assume that participating in the current research project was the biggest research activity that they could manage at this stage. Despite their lack of interest or commitment in developing their own research project at this stage, the interest and enthusiasm they showed to the researcher need to be acknowledged. It suggests that there was a desire and demand to get involved in research activity. The CNC expressed her interest in how the nurses found the ACP and its impact on them in order to facilitate and accommodate them into the ACP. Hanna said:

*I think for every Plan of Treatment I want to talk with the nurses and find what their feelings are about it and recognising that they might have very difficult, different concerns or attitudes. It's probably airing some of those and not saying 'Well this is right or that is wrong, or the patient is right and you're wrong, or vice versa'. It is getting them out and saying 'Well yeah that's your feeling. This patient felt differently. If it came to Saturday night and there was no one around to ring up and check about what to do now, would you be able to follow this directive? And if not, why not.' And that is the stuff that you have got to embed and sort of pull out or unpack a bit more as well too. I don't think I have got any higher ethical or moral thoughts than the next person, so it is getting that breadth of understanding across from lots of nurses from different cultures, from different areas, to understand. And at least if we talk about that, often it is just that talking again about what I value and what you value, we can find common ground. And I might say 'Look, I don't want you imposing your wishes on me just like you don't want my wishes imposed on you' (RN 25: Hanna: CNC).*

An RN emphasised that how important it is to have the expert nurse and the current research project to collect scientific evidence that can be distributed to the general population in order for them to think about end-of-life care preferences and to make an informed decision. Carla thought:

*She (Hanna) would be a great mentor for people. You need to have right, she has got a wonderful personality. You need to have the right people. It is like a social working skills, can be empathetic but intelligent at the same time and not preempt what people want. (Would) Like to ... **research skills**, to put it in such a way that you are eliciting what they want about guiding them. Do you know I mean? ... // ... Hanna, she does a lot of work but she is the only one in NSW unbelievably. **We need a lot of evidence that what she is doing is important** and we need more like her. And this (the interview) is part of that evidence, making evidence formal and available ... // ... it maybe, it's something I really believe in. I think what you are doing (the current research project) is great and I think, it's highlighted to me working here how important it (ACP) is. I would never have even thought about that. And that's unfortunately for most people, they don't think about things until they are in that situation (RN 3: Carla).*

## Conclusion

The ACP program as a pilot project required the expert nurse and the RNs to challenge themselves and to expand from their previous roles and function to an unknown extent. The data collected generated complicated and intricate images in relation to the nature and scope of nursing practice in ACP. Therefore, it was inevitable that the images collected needed to be edited, highlighted, excerpted, contrasted and discarded in order to project new images in relation to the scope of nursing practice. The images collected were illuminating and assisted in the development of the 'Nursing Brokerage Models A and B' (Figures 5 – 2 and 5 – 3) and, together with the 'Nursing Roles and Functions Model' (Figure 5 – 4), allowed the researcher to more fully articulate the scope of nursing practice in ACP. Analysis of data collected from the scope of nursing practice in ACP revealed that:

- Nurses' roles and functions underpin that ACP is not 'a product for sale' but 'a process to promote health and well-being'.
- The expert nurse's role was emphasised in that without expertise in implementing ACP, it is difficult for residents to think about 'what I will be' and even harder to conceive of 'what I will do when I am not myself'.
- Nurses need to be better prepared for the role in that initially, in the conception of role in RACFs in Australia, there were not many residents who were competent to document ACDs and there were not many families who wanted to know more about ACP.
- Education was one of the most important functions in the ACP processes.
- Everyone was passing the buck on this important issue; there was no understanding of each other's roles.
- The RNs' roles in ACP processes were minimal and limited.
- Routinising ACP processes and having one designated person responsible for implementation is desirable.
- There was acknowledgement that RNs were not research-active.

It was concluded that the expert nurse has played significant roles in the implementation of ACP process in RACFs. She not only functioned as a facilitator and a broker but also covered a wide range of major functions from the lowest to the highest levels in the 'Nursing Roles and Functions Model'. This in fact was almost a 'mission impossible' or far

from complete, as she was covering such a broad area by herself, and as there was an absence of someone who could play her extensive role in facilities. It was suggested that she would mainly need to focus on the facilitation and brokering of ACP and that the RNs in facilities would need to be more educated and actively involved in initiation, discussion, and documentation of ACD and POT. Therefore, the new perspective emerging from the images of scope of practice was that it would be ideal to have a 'team leader' or a 'champion' at facility level, someone from whom the RNs could seek help if necessary before turning to the CNC.

The managers took responsibility in initiating the discussion on ACPs with the residents and families. Counselling and supporting them were also important functions with which the managers were engaged. The policy and manuals were in place in each facility to support the staff members with ACPs, as the managers were committed to improving end-of-life care in the facilities for the residents, families, and staff. It was suggested that ACP on admission and in follow-up phases needed more systematic approaches by the managers and the organisation.

Overall, the RNs, the managers, and the CNC have contributed a great level of knowledge, skills, and team work in the implementation of ACP and the use of ACDs/POT. Their levels of functions and expertise have had a significant impact on the outcomes and experiences with ACP of the residents, family members, and even nurses themselves. The scope of nursing practice in ACP in RACFs provides nurses with more opportunities and with challenges that they need to work with. It was apparent that nurses were aware of the new roles and functions emerging and that nurses expressed their willingness to commit themselves to their expanding responsibilities. The findings of the current study provide nurses with feedback on how the ACP can be better implemented and practised. It is only now a matter of when and where we commence.

The entire image of the nurses' roles and functions in ACP is presented by introducing four exemplars in Appendix 19. The exemplars are chosen to demonstrate how the CNC helped an individual to complete ACDs and what the processes involved. The exemplars represent the typical situations that an individual was in, the activities that the CNC, the RNs and other members in the health-care team performed, and the outcomes achieved by documentation of ACDs.

The researcher has presented the findings in relation to the implementation process of ACP and the outcomes of ACP in chapter 4. In chapter 5, the researcher described the experiences of residents, family members, and RNs with ACP and the scope of practice for the nursing profession in ACP in RACFs. The following chapter presents an in-depth discussion of the issues that emerged from the findings and the nursing implications for practice and research. Chapter 6 concludes the thesis with a montage of the phenomenon of ACP in RACFs in 'A Nursing Theory of Gerotranscendence/Successful Dying in End of Life through ACP'.

## Chapter 6

### Discussion, Implication, Conclusion and The Montage

#### Introduction

According to anecdotal data, there was concern about the way in which the end-of-life care was delivered to the older people in RACFs. Nurses in RACFs have also been asking themselves if the care they provided was what the older people or family member would have wanted. Advance Care Planning was implemented by one CNC in RACFs in NSW, Australia in order to improve end-of-life care for older people and their family members in RACFs by giving them an opportunity to clearly express their views on what treatments they would or would not want.

The current research is the first formal investigation into how the ACP program was implemented and accepted by the people who participated in the program. The researcher has presented the data on the implementation processes of ACP and the outcomes of ACP on the study participants (residents, family members and nurses) in Chapter Four. The experiences of these people with ACP were fully described and the elements of scope of *nursing practice in ACP* that emerged were explained in Chapter Five.

In this chapter, the researcher discusses the issues that derived from the findings, that is those that require further interpretation and examination. Each research question is discussed in depth from the researcher's interpretive viewpoint and with reference to the relevant literature. Table 6 – 1 depicts the issues raised in relation to each research question.

**Table 6 – 1. Research questions with the issues that emerged**

Research Questions	The issues
1-1. Why are ACP and the use of ACDs implemented by the CNC in RACFs?	6.1.1 Is ACP undertaken in a timely fashion? When should ACP begin? 6.1.2 How do we best capture what residents and families want?
1-2. How are ACP and the use of ACDs implemented by the CNC in RACFs?	6.1.3 Four key determinative requisites (the expert nurse, discussion, education, multidisciplinary teams)

2. What are the outcomes of ACP for residents, family members and RNs?	6.1.4 Autonomy in the social context 6.1.5 Change of culture and attitudes towards dying/death/ACD/POT
3. How do residents, family members and RNs perceive their experience with ACP in RACFs?	6.1.6 Gerotranscendence experienced by residents, families and the RNs 6.1.7 A 'do-it-yourself' approach
4. How is the scope of nursing practice perceived by the CNC and the RNs in ACP in RACFs?	6.1.8 Boundaries, discrepancies and a shift of responsibility in roles and functions 6.1.9 Lack of time, knowledge, skills, experience and confidence 6.1.10 Designating and delegating

## 6.1. Discussion, implications, and recommendations

### Research Question 1 – 1: Why are ACP and the use of ACDs implemented by the CNC in RACFs?

#### 6.1.1 Is ACP undertaken in a timely fashion? When should ACP begin?

One of the important queries that was identified as needing further discussion was 'Is Advance Care Planning undertaken in a timely fashion?', and 'When should ACP begin?' The researcher reveals how the question of 'why' ACP is linked to the 'when' of ACP, as it was a concern for nurse participants and also has significance in nursing practice.

The data revealed the reasons for initiation of ACP for residents and/or family members. The residents with end-stage dementia or other debilitating and degenerative illnesses presented signs of deterioration such as frequent aspiration pneumonia and urinary tract infection (UTI). They often had to be transferred to the hospital simply for IV antibiotic treatment. When the older person was sent to the A & E in the hospital there was an horrific experience awaiting them. They were left in pain and discomfort on a trolley for hours and hours while the doctors and nurses were attending patients with more serious and urgent needs. Their aggressive and disruptive behaviours arising from exacerbated confusion and discomfort with an unfamiliar environment caused hostility and an unwelcoming attitude from hospital staff, who were saying; 'Do not send him/her to hospital. There is nothing we can do'. The repetitive and frequent hospitalisations without improvement were described by the nursing staff as representative of 'suffering' and it



posed serious questions for the staff in the facility. If such exhaustive care were to be provided, was that what the older persons would have wanted if they were able to speak for themselves? If the family member was making demands, was this what their loved ones would have wanted? The staff wanted and needed to provide the care that was wanted by the older person and the care that would benefit the resident, not to prolong suffering. The nurses believed that residents' and/or family members' wishes for care were revealed through ACP. ACP has also given nurses some directions on what was and was not acceptable for an older person at the end of her/his life.

However, as the data disclosed, it was not until the resident's health deteriorated that ACP was offered to the resident and the family members. It meant that not many residents in RACFs were legally capable of documenting ACDs and that family members were asked to speak for the residents when they were in distress and feeling emotional because their loved ones' condition was deteriorating and they feared the imminent death of the loved ones. It also meant that ACDs and POT were considered as a 'palliative care order', which meant the concept of ACP had not been fully captured in practice. ACP was implemented in order to improve end-of-life care for residents by giving them an opportunity to express their wishes. However, **one still needs to ask if Advance Care Planning had been undertaken sufficiently in this situation.**

The nursing staff in facilities reported that if an older person was happily demented and did not require medical attention, ACP was not necessary or that they found it difficult to initiate ACP. It was assumed that residents and families would not accept or not be interested in being involved in ACP when it was attempted while the older person was still well and capable. For example, Theo, who was a dedicated carer for his sister Tia, wished that he had discussed the matter with his sister while she was able to express herself. But then he expressed his concern that he would have felt guilt if he had documented ACDs with Tia, as it could be seen as giving up on her or pre-empting possibilities too early, considering that Tia was in her early 30s at that time. This response was consistent with that from previous studies. The age of an individual and the encounter with the painful death of loved ones have correlated with the documentation of ACD (Bravo, Dubois & Paquet, 2003; Hopp, 2000).

Whilst some nurses mentioned that residents and families would not be able to relate to ACP or would not want to discuss it prematurely, other nurses believed it to be too late to talk about end-of-life care wishes when the residents were 'at the end of life'. Professor Abbey pointed out in an interview with Mogg (2006) that it is often too late by the time a person moves to the acute or residential setting, as the capacity of the person to make wishes known has already been lost. On the other hand, the studies undertaken by Kirk, Kirk, and Kristjanson (2004) and Hagerty, Butow and Ellis et al. (2004) suggested that health-care professionals to consider raising end-of-life discussions if the patient is expected to die within 6–12 months.

In the current study, the response from the participants varied on when and how far in advance ACP and discussion of ACD should be initiated. Some reported that the family should have been given full information and an opportunity to discuss by the hospital staff while an older person was in hospital with an acute illness, given that the likelihood that they would be hospitalised again. Others reported that ACP should not be mentioned unless the resident showed signs of decline and faced no prospect of future medical intervention. On the other hand, nurses were concerned that discussions of end of life care and treatments with residents and families were left too late to be meaningful in terms of the philosophy and intent of ACP. At the end stage of life residents were not able to make decisions for themselves because of cognitive impairment. Family members were also too distressed to make 'conscious' decisions.

Therefore, appropriateness of timing on ACP is questionable. These nurses suggested that older people and families should be given a chance to explore their preferences on care options while they are capable and living in the community. Another suggestion was that there should be a routine process on admission to fully explore and discuss treatment options with older persons and the significant family member. This suggestion was opposed by some RNs, as admission to a RACF would already cause a hardship to some family members who would be offended by the conversation about dying and death.

Consistent with previous research (Carr & Khodyakov, 2007; Lambert et al., 2005), this study found that there is no 'one-size-fits-all approach' to end-of-life planning and health professionals need individualistic approaches. There is no one definite answer about when ACP should be initiated and how far in advance the discussions about end-of-life care

should begin. However, it was agreed that there should be a routinised/formalised process at the organisation level in residential care for initiation of the discussion on admission and for follow-up processes on a regular basis, for example, at six weeks, six months, or after an episode of acute illness or an event. With this formal process in the organisation's system, initiation of ACP requires person-centred approaches to the timing of initiation of ACP, given that the individual's preference of timing of the discussion or acceptance of the discussion may depend on where they are in life and whether they have faced a death of someone close before. It also indicates that indirect experience with death and dying can help reduce unknown fears or misunderstandings of the dying process. This finding is consistent with literature (Vollandes et al., 2007; Westley & Briggs, 2004) that using materials such as videos and scenarios developed to promote ACP might help them prepare and initiate the thinking.

#### **Recommendations for nursing practice**

1. A formalised routine process on admission to explore if one has already ACDs documented, and if not, if one is interested in being involved in ACP is suggested to initiate ACP. This will ensure that no one misses the opportunity to know what ACP is and what it can do for residents and family members. The older person may not be capable of participating in discussions, however, the routine process should promote opportunities for the family to make conscious decisions that represent the best interests of the older person while they are not in distress and feeling emotional.
2. The past experience with death and dying, and the perspectives on their current life are good indicators of how they may respond to or accept ACP. Nurses should take these into account and take an individual approach (person-centred approach) within the formalised routine processes in inviting people to participate in ACP.
3. Nurses are in the best position to capture the individual's preference on the timing of end-of-life care discussions due to their long-term and consistent relationship with residents and families in RACFs. Residents or families might simply mention their experience with the death of someone close, the life in RACF, use of morphine, palliative care or hospitalisation. Nurses can also use these prompts to gauge how the residents and families might respond to ACP. Nurses need to recognise these and any other cues that might indicate readiness for discussion about ACDs of residents and families.

### **6.1.2 How do we best capture what residents and families would want?**

Another reason emerging from this study for the implementation and initiation of ACP was to promote the autonomy of the older person (NSW Health, 2004). Residents in RACFs have had their rights taken from them in many ways. They have lost the right to stay in their own home to start with and did not have control of decision-making, even on a minor decision, such as when to get up and what to basically eat. In fact, most older people in RACFs were considered legally incapable of making any decisions for themselves, due to cognitive impairment. In this regard, ACPs were welcomed, given that they had given the residents their rights back with regard to decisions on what they wanted or did not want at the end of life, while they were still capable, or when their substitute decision-maker had a clear right to represent the best interests of the older person. However, it is crucial to inquire how residents' wishes were captured and how families represented the older person's best interests through ACP when they were given the right to express these. The current study revealed that there were a number of strategies taken by the expert nurse.

Rather than simply asking if an older person wanted to be resuscitated, the expert nurse used a 'Values Clarification Worksheet' and 'Nursing Home Project Assessment Tool' to explore what an older person valued in life, how the person made decisions in life, what medical intervention was un/acceptable for her/him, how the person coped with the changes in life, and what was important at the end of life. These assessment tools were also used for family members to help reflect just who the older person was, how s/he had lived life, and what had been important for the person. She was highly committed to 'Information acquisition' (see Figure 5 – 2 and 5 – 3) to extend her understanding of each older person before proceeding with documentation of ACD/POT. The information was collected through verbal and written reports as well as observation, and included retrieval of the essential entity of the person, current functional status, and preferences for care. This process has taken significant time. However, it has never been overlooked by the expert nurse. This personal approach that the expert nurse undertook is supported by previous studies in literature (Bickerstaff, Grasser & McCabe, 2003; Douglas & Brown, 2002; Steinhauser et al., 2002).

Theoretical and philosophical explanations for her distinct approach are underpinned in the 'continuity theory in ageing'. According to Atchley (2001), a large proportion of older people demonstrated a considerable level of consistency in their patterns of thought, behaviour, and relationships, despite dramatic changes in health, functioning, and social circumstances as they aged. The level of consistency is derived from the tendency of the use of the first-line strategies by the old people that were developed for a lifetime by constant revising and refining one's robust patterns of thought and action for planning, making life decisions, and adapting to life changes. It also produces the origin of one's sense of security, the mean of life transition, and the buffer of the effects of life changes (Atchley, 2001; Kaufman, 1993; Lambert et al., 2005).

Continuity theory does not mean absolute stability or absence of change, but in the most elaborated form, it is defined as a social-psychological continuous development and relatedness over time (Atchley, 1989, p. 183). The heart of continuity theory lies in its use of feedback systems theory to create a view of adults as dynamic, self-aware entities who use patterns of thought created over their lifetimes to describe, analyse, evaluate, decide, act, pursue goals, and interpret input and feedback (Atchley, 2001, p. 246). Therefore, the use of the 'Values Clarification Worksheet' and 'Nursing Home Project Assessment Tool' through an extensive 'Information acquisition' process by the CNC in order to explore how an individual defines her/himself, what patterns of thought had been created over a lifetime, and how the patterns of thought would act on end-of-life care decision-making is clearly justified and endorsed. The CNC was able to monitor during the 'Information acquisition' process whether the older person wanted to make a radical decision, if the decisions that the person wanted to make were consistent with how s/he had generally believed. The CNC was also able to see if there were a discrepancy between who the family members said the older person was and what the family wanted for the person. The concerns and worries over the possibility of ACD being misused by some family member who wanted to take advantage of financial benefits by the death of the older person are taken care of by this step in the ACP process.

However, one needs to ask how much relatedness is needed over time in order to qualify as continuity. In other words, how do we capture one's self-aware entity and how much information is enough to conclude that the person's essence of being is entirely captured? How likely is the person going to change what is documented? In the literature, the validity,

reliability, stability, consistency and currency of ACDs are seriously questioned and criticised (Allen et al., 2003; Bravo, Dubois & Paquet, 2003; Hopp, 2000; Frank et al., 2003; Lambert et al., 2005). The difficulties, recognised by health-care professionals, with ACP, include determining whether a person's wishes as set out in an ACD match the clinical situation that requires execution of the ACD, exploring if the person changes her/his mind, maximising how family members best represent the person, and losing the person's capacity to make decisions (Mogg, 2006). It has been a constant concern for health-care professionals that residents' wishes may change through time as conditions and quality of life change (Wurzbach, 2002). For this reason, it is important to explore the implications of continuity theory for nursing profession.

According to Atchley (2001), there are four elements that constitute continuity. Elements of continuity theory include internal structure, external structure, goal setting and maintaining adaptive capacity. First of all, people collect and store ideas, mental skills, and information, which then are structured as self-concept, personal goal, worldview, philosophy of life, moral framework, attitudes, values, beliefs, knowledge, skills, temperament, preferences and coping strategies. Each individual develops and becomes the 'essence of being' by forming and containing different dimensions in these structures in a unique way, which then distinguishes one person from another. The **inner structures** are achievements and strategies that were developed by a lifetime of trials and errors, hence people maintain the inner structures in making life choices and in adapting to changes (Atchley, 1987, 1989, 2001; Kaufman, 1993; Lambert et al., 2005). This element justifies how important it is to identify an older person's inner structure in ACP, as it will provide an insight of what the older person will choose at the end of life and how s/he will cope with the situation.

In addition to internal structures within oneself, people exist in social roles, activities, relationships, living environments, and geographic locations. Each of these **external structures** are prioritised and selected in order to produce the greatest possible satisfaction for them within constraints. People continue their activities and relationships in environments where they can minimise social, psychological, and physical losses, and where they have strong social support to create and maintain solid concepts of self and lifestyle (Atchley, 1987, 1989, 2001). Therefore, it is understandable that the participants in the

current study needed to include someone from their own social structures and relationships in end-of-life care decision-making.

Continuity also lies in the fact that people **set goals** to evolve in themselves, their activities, their relationships, and their environments. They make decisions to achieve the goals set up, for example, on which aspects of themselves to focus their attention on, and which activities to engage in, based on socialisation and life experiences (Atchley, 1987, 1989, 2001). This element points out that it is important to explore what an older person wants to achieve in life and how nurses can help an elderly person achieve the goals they had set up in life with ACP and ACD.

As a result of lifetime learning, adapting, personal evolution and selective investment, people have an **adaptive capacity to maintain** the internal and external structures that give them the maximum life satisfaction possible, given their circumstances. Therefore, it is only natural that in adapting to change and in making decisions, people continue to use the internal and external patterns on which they have spent so much time and from which they have achieved the best outcomes (Atchley, 1987, 1989, 2001). Therefore, it is important for nurses to identify the resident participants' own adaptive capacity that they have developed over their life-time and to help them continue to use it for the end-of-life care planning.

An acknowledgement of patients' beliefs and concerns has been found to be lacking in physicians' approaches to ACDs, even though these values are recognised as important predictors of treatment preferences (Crawley, Marshall, Lo & Koenig, 2002; Steinhauser et al., 2000). It is concluded that four elements of continuity theory would increase the validity and consistency of ACDs/POT if addressed comprehensively. By drawing out individual's internal and external patterns in attitudes, behaviour, values and relationships over multiple points in time, and by exploring life experience and social boundaries that may affect decision-making, nurses are able to minimise radical decision-making for end-of-life care and maximise consistency and continuity where the person maintains the solid essence of being and dignity. Clayton et al. (2007) recommended that health-care professionals should develop an understanding of the person's values and help her/him to work out goals and priorities related to her/his remaining life and treatment of the illness, and document the person's preferences. This recommendation is supported by Bickerstaff, Grasser and McCabe (2003) in that the validation of goals and values remains essential to

the well-being of the older person in a long-term care facility. Lambert et al. (2005) also suggested that health-care professionals should interview residents to find out exactly what their values and beliefs are, and what experiences in their lives are likely to influence the decision for or against various treatments.

Some may question the attempts made by the CNC to use the 'Values Clarification Worksheet' and 'Nursing Home Project Assessment Tool' during the 'Information acquisition' stage and whether these captured one's 'essence of being' and if the ACDs/POT documented fully reflected one's genuine essence of being and wishes to the full extent. The actual number or percentages of older people who changed their end-of-life wishes is not available in the literature. However, the current study revealed that ACP and the use of ACDs/POT with these two assessment tools reflected successful 'continuation of oneself'. None of the residents or family members who completed ACDs/POT since the ACP program was implemented, had made a request to change or revoke the documentation.

Decision-making processes in ACP are not simply focused on whether the person wants a feeding tube or not, but rather is a sensitive and complicated process that involves reflecting one's essence of being and continuity close to and at the end of life. As there is no consensus among experts regarding the amount of assistance that should be given by a professional (Ford, Schofield & Hope, 2003; Inman, 2002), the needs of individual persons should be respected, instead of expecting everyone to make their advance directives with the same assistance from staff within the same restrictive timeframe. An organised and time-limited ACP process suggests contrary findings to the implicit and protracted decision-making process, which suggests the decision-making process should be attempted according to each individual's wishes (Rosenfeld, Wenger & Kagawa-Singer, 2000; Wurzbach, 2002).

#### **Recommendations for nursing practice**

1. The likely change or consequences of having or not having certain medical intervention at the end-of-life needs to be assessed by nurses in relation to the themes of one's continuity or past patterns, as the personal systems, beliefs, and values offer the highest probability for successful 'continuation of oneself'.
2. Nurses need to understand and apply the relevant principles and appreciate the



implications of continuity theory of aging with decision-making in ACP.

3. Nurses should consider four elements of continuity theory, which are internal and external structures, goal setting and adaptive capacity to maintain, in ACP in order to help the person make decisions that are consistent with her/his essence of self-being and achieve the continuity of self-entity through ACP.
4. Nurses need to help family members assess their loved one's 'essence of being' along the continuum and assist those family members in end-of-life decision-making in a manner consistent with 'continuity of the person'.
5. Nurses should be confident in assessing and communicating the person's values, goals, and priorities in relation to treatment preferences for the remainder of their life.

### **Research Question 1 – 2: How are ACP and the use of ACDs implemented by the CNC in RACFs?**

#### **6.1.3 Four key determinative requisites**

The first study in Australia to examine the uptake of ACP in response to education has brought up an interesting discussion on how ACP should be implemented and what may constitute successful implementation. Mador (2001), who was a registrar in geriatric medicine, interviewed and provided 40 people aged over 60 years who participated in inpatient and outpatient rehabilitation programs in a region in NSW, with verbal and written information about the ACP program. Overall, 30 (75%) demonstrated a good level of knowledge of Enduring Power of Attorney, only one (2.5%) knew about Enduring Guardianship and one (2.5%) knew about ACDs at the baseline interview. Then the participants were offered a brief discussion about the various options for ACP and how to complete formal documentation. At the end of the interview they were given written material on Enduring Power of Attorney and Enduring Power of Guardianship published by the Guardianship Tribunal of NSW. Thirty-four patients were successfully followed up one month later. Among the 14 (35%) who completed further documentation, 10 participants appointed an Enduring Power of Attorney for their financial arrangements whilst 3 participants documented Enduring Guardianship form and one documented an ACD. It was concluded that knowledge and uptake of Enduring Power of Guardianship

and ACDs were very poor prior to the intervention and did not increase substantially (from one to four), even after education and brief discussion.

The current study supports the findings from Mador's (2001) study and elaborates what is required in helping people with ACP. It became evident from the data collected through observation and interview, and the images that emerged through analysis of the data that there were **four key determinative requisites** that brought a success in ACP implementation process. These are the expert nurse (CNC), discussion, education and multidisciplinary team (PACS, palliative care team, GP and managers). The conceptual framework in Figure 4 – 1 depicts how ACP and the use of ACDs were implemented by the CNC in RACFs. The implementation of the ACP process has been elaborated in Chapter 4.

The data revealed that there were resources required to support the ACP process and elements to work with or through in ACP processes. One of the most significant resources identified was **the expert nurse herself**, who initiated the implementation of ACP in RACFs. The expert nurse facilitated and brokered the ACP process in RACFs. As a facilitator she recruited the managers who were interested in implementing ACP in their facilities and helped them establish the systems in place to practise ACP. The development and inclusion of questions related to ACP and ACDs in the admission paperwork, and of the organisational policy and manual were examples of the systems set up in the facilities. As a broker, the expert nurse advertised the concept of ACP through education, collected all the information needed for ACP, determined goals and plans and, using her clinical judgment, brought the multidisciplinary team together, mediated among the people (the resident, family, nursing staff, managers, GP, palliative care, PACS team, specialist) involved in ACP, and advised people with regard to problems, difficulties, law and ethics in ACP and ACDs. Her contribution to the implementation of ACP was highly appreciated by the people who participated in the process. It is evident in the comments made by the participants, for example, 'we need to clone her', 'she has been like a white light', 'everyone (every resident) should see the CNC', and 'I make a referral to the CNC'. This finding is outstanding compared to the findings of Inman's study (2002). In her study of 55 adults aged 50 or over, only eight per cent indicated nurses as the desired educator for ACDs. The result is disappointing but not surprising, considering that the roles that nurses played in

her research setting was focused on measuring the effectiveness of education after completion of a formal document.

Another distinctive requisite in successful implementation of ACP was '**discussion**'. It has been noted in literature that the *Patient Self-Determination Act* (PSDA) does not promote discussion or increase the documentation of ACDs (Hahn, 2003; Inman, 2002). One of the criticisms about ACD in America was that its focus was on the tick-off box and paperwork. In contrast, the CNC, who was the vital person in ACP, has heavily concentrated on the person and the discussion in the process. It was the discussion among older persons, family members, the CNC, managers, RNs, GPs, and other specialists, if necessary, that restored the autonomy of the person and the promoted the health and well-being of the person. The older person and family members were fully informed before they made decisions during the discussion about what options they had, what the benefits and burdens of each option would be, what they would/would not want, what the consequences of their choice would be, what could be done in the facility, and how their wishes could be achieved.

Documentation of directives was not the main goal of ACP rather it aimed to provide an older person with a chance to maintain one's essence of being, and a family member with an opportunity to act for the best interest of her/his loved one. It was during the discussion that the values, beliefs, attitudes of the older person were explored and reflected by the person or the family member in the ACDs/POT. It was the discussion that prevented someone from misusing or abusing ACP to hasten death by posing questions, for example, 'how important is it for you to be able to recognise your family or friend?', 'why is it important for you (or your mum) to be independent?' and 'what if you have your leg fixed with an operation but you need help from others to shower or to feed yourself?'. These questions were crucial, given that residents and families demonstrated difficulty understanding with what it meant to live with dementia, how it would progress, what I (resident) would want for me when I would no longer be myself, and what I (family) would do for mum/dad who was not able to say what s/he would like.

Discussion was also important in that the written materials available have failed to increase the residents' and families' level of understanding. It was not until that the expert nurse helped the residents and families with the more abstract thinking during discussions that they were able to document their wishes in ACDs or a POT. Discussion provided everyone

involved in the care of the older person with a chance not only to explore the best options for the person but also to express how each one felt about the process and the decisions made. Therefore, the discussion process prevented a conflict, revocation, or emotional turmoil but generated agreement and concerted actions from all parties involved.

Another key determinant for success in the implementation of ACP was **'education'**. Wurzbach (2002) found that education for the resident and family was essential, as few residents know or understand the prognosis of having CPR or withholding/withdrawing treatments. The main contents of education sessions in this study were the concept of ACP, prognosis of dementia and other degenerative diseases, consent, substitute decision-maker, *Guardianship Act*, various levels of care, and consequences of each level of medical intervention. The importance of educating people about the concept of ACP and the use of ACDs was highlighted for a number of reasons in this study. First of all, people, including residents, families, nurses, and GPs hardly knew what it was, what difference it would make, and how it could be applied in practice. Secondly, there also existed myths about ACP that it is a kind of euthanasia, negligence, or assisted suicide. It was not until the expert nurse provided residents, families, and especially RNs in facilities with in-service education sessions that they understood what it was and felt comfortable discussing end-of-lifecare treatment options. Most importantly, residents and families were educated that ACP represented their right to express what they would/would not want at the end of life. They had to be empowered and enabled through education to execute their right to make decision for themselves. This finding is consistent with the result from Krynski, Tymchuk, and Ouslander (1994) in that older people's knowledge increased significantly after an educational intervention, particularly if the intervention involved multiple conversations with the older adult and simplified, illustrated educational material. The RNs were educated that it was not nurses or doctors but residents and families who would give them directions for the care of the older person and that nurses were responsible to make sure residents' or families' directives were respected. It was a critical change of culture in that it was residents' and families' right and responsibility to make decisions, not doctors' nor nurses', in fact no one else's but residents' and families'.

However, it was not an easy or quick process in which residents, families, GPs and RNs embraced the concept of ACP and wanted to accept the use of ACDs, due to the myths and misunderstanding about ACP. The CNC delivered education sessions focusing on

what ACP could do for residents and families, what support services were available from the hospital to residents in a facility, how health-care professionals could promote health and well-being rather than focusing on death, dying and end of life. Interestingly, old people themselves, either in low-care facilities or in the community, were willing to know more about ACP and to proceed with ACDs. However, it was the families, GPs, and nurses who were reluctant to learn about or discuss ACP and ACDs. This is consistent with the study undertaken by Cartwright (2000). It indicates that it is easier or more ideal to make decisions for oneself than for somebody else, because of the possibilities of misrepresenting the person, litigation and violation of autonomy.

The last requisite that has a determinative effect on the implementation of ACP in RACFs is the involvement of the **'multidisciplinary team'**. The multidisciplinary team includes the Post Acute Care Service (PACS) team, palliative care team, GPs, other CNCs, neurologist, psycho-geriatrician, and geriatrician. The multidisciplinary team care is a key ingredient in health care for people with chronic conditions and multiple co-morbidities, as these patients present a range of problems that affect all dimensions of human experience and that require the expertise of many professional disciplines. Nevertheless, multidisciplinary team care is in general not well represented in either the health-care system or in the published literature with regard to how the multidisciplinary team is involved and what it does in ACP (Connor et al., 2002).

In the current study, it was critical to have the multidisciplinary team in ACP in Australia. The participation from GPs was essential, given their long-term relationship with the older persons and families in the local area and that they would be the ones who have legal authority to send or not send the person to hospital, and to make or not make a referral to palliative care and PACS teams. If GPs believe that it is best if the older person is sent to hospital, when the person or the family wants palliative care in the facility, the result of the inconsistency would be costly economically, physically, psychologically, emotionally and spiritually.

The care services from palliative care and the PACS team from hospital to the residents in facilities have provided family members with great relief, as their utmost hope to get their loved ones treatment from hospital was achieved. The wishes to not be sent to hospital, or to be treated palliatively, and to not be fed through tubes could not be achieved without

the involvement of palliative care and PACS teams. The findings of the current study is supported by Connor et al. (2002) in that no individual team member alone can meet the needs of highly complex older persons and families facing the most difficult passage of a lifetime.

#### **Recommendations for nursing practice**

1. There are four determinative requisites for successful implementation of ACP in RACFs: the expert nurse, discussion, education and the multidisciplinary team. Nurses need to consider these four factors when expanding ACP into other RACFs.
2. The nursing profession should act on the fact that nurses who are qualified and educated to expert level need to be more available to expand ACP to the broader area in Australia.
3. The implications of having discussions on the ACP process are invaluable, despite the fact that it is time-consuming. Nurses should not overlook the benefits of having discussions with everyone involved in the care of the older person and should play an active role in initiating and participating in discussions.
4. Education is essential in ACP in order to correct myths and misunderstandings about ACP, to fully inform about treatment options and their consequences, and, more importantly, to empower people to practise their right to make decisions. The nursing profession should respond to the request from nursing practice and increase the number of nurses at an expert level who can perform this role.
5. Having the multidisciplinary team available for residents and their family members in RACFs is essential in providing them with utmost hope. The nursing profession is challenged to redefine its roles and functions if it is able to provide the residents and families with the levels of care desired in the facility.

**Research Question 2: What are the outcomes of ACP for residents, family members, and RNs?**

#### **6.1.4 Autonomy in the social context**

Nurses were concerned that some care given to the residents at the end of life could be exhausting and futile and not what they would want for themselves or for their loved ones. They were in an ethical dilemma about whether they were doing more harm than good by

delivering care without knowing what the residents would have wanted or the families would have wanted for the residents. Despite the above concern, nurses had to fulfil the legal and professional duty of care to the residents and the family members. For this reason, ‘autonomy’ or the ‘right to make decisions’ had significance in one of the outcomes of ACP. The residents had the right to make their own decisions or the family members had the right to make decisions as substitute decision-makers for their loved ones through ACP. Therefore, the residents or the family members made decisions on what was wanted and not wanted at the end of life and nurses were given clear directions of what to do and not to do. Indeed, the directives written in ACDs or POT have rescued the nurses from the ethical and legal dilemma of what they need to do to fulfil the duty of care and what they did not want to do, given the invasiveness of care at the end of life.

Autonomy embraced in ACP has two important implications for nurses. First of all, the residents and the family members had to be **empowered and educated** to accept and to execute their right to make decisions for end-of-life care preferences, as their autonomy to make decisions for health care has not been in their hands for a long time (Cartwright, 2000; Wurzbach, 2002). It was also often expressed that older people are intimidated by professionals and lack the sophistication and vocabulary to express their desires in a rational and assertive manner (Gerber, 1995). Considering that they had the right to make decisions back in their hands all of a sudden and that the decisions they were asked to make were the kind of decisions that needed comprehensive education about the nature, extent and consequences of those decisions. It was intensely empowering for them to be comfortable with the decisions they made in ACDs or POT.

Secondly, autonomy for residents and family members needs to be understood in the **social context**. Autonomy is often referred to as ‘self-determination’ (Inman, 2002; Wurzbach, 2002). For example, Wurzbach (2002) found that 79 per cent of 135 nursing homes in Wisconsin reported that the residents with or without ACDs were the primary decision-maker, rather than the family or physician. Consistent with this, in the current study, the residents who documented ACDs claimed that it was their right and responsibility to make decisions for themselves and that it should not be left for someone else to make decisions for them. However, written the end-of-life care wishes had never been decided by one person, but were the results of a number of discussions with everyone who was involved in the care of the older person.

It was interesting to note that the older person who was capable of making decisions for her/himself did not make end-of-life care wishes alone but did discuss with significant family members the decisions they wanted to make. The older person finally made end-of-life care wishes known, but her/his family members were involved in the discussion and their support and involvement were reflected during the process. The family members who were representing an older person did discuss the issues and concerns with other family members before they finally signed on the POT form. If s/he was a single child, then guidance and support were sought from nurses and GPs. Nurses encouraged the residents and family members to discuss the issue with other people who were involved in the care before they put something in writing. It indicates that an individual as a social being would need support and confirmation from others in the social context that s/he was in to practise the right to make end-of-life care decisions. In other words, it was not until they had someone in their close social context to be with them and to support their decisions that the autonomy of an individual was executed in ACDs. This is consistent with the theory of 'continuity of ageing', in that people continue their relationships in a social context where they can be granted social support to maintain self-entity (Atchley, 1987, 1989, 2001). Therefore, autonomy of an individual in ACP should be understood and promoted within the social context of the person.

#### **6.1.5 Change of culture and attitudes toward dying/death/ACP/POT**

Another outcome that was highlighted by the data was that there was a **change of culture and attitude** towards death, dying, and end-of-life care decision-making. The culture of 'Don't go there' represents a belief that death and dying have been taboo subjects for a long time in human history. The culture of 'Do everything' has been a defence to overcome the helplessness and fear that were brought up by the nature of the inevitability of death and dying (Cartwright, 2000). In the current study, these two elements of culture were clearly noted and considered as major barriers in the ACP process. However, the culture of 'Don't go there' was changed to 'Go there and discuss it', and 'Do everything' was changed to 'Do only what the person wants'. Therefore, it requires further discussion on what the causal factors of these cultural changes are, and how ACP has contributed to the changes of these cultures. The discussion on these issues will highlight implications for nursing practice.



Family members and nurses in facilities were reluctant and uncomfortable with fully exploring end-of-life treatment options on admission. The reasons given to the nurses were that family members did not want to talk about end-of-lifecare options, especially not at the time of nursing-home admission, because a) the resident seemed to be doing better now than when they were in hospital for acute illness, such as a stroke or a heart attack; b) they were too distressed with the nursing-home admission; c) they could jinx or hurry up the loved one's death by doing ACP, hence they **did not want to go there**. It indicates perpetuation of the myth that ACP is to be undertaken when the dying process has progressed and imminent death is expected. This finding is consistent with and additional to the knowledge built up in the current literature available. The current literature suggests procrastination, discomfort, lack of awareness and lack of necessity as major reasons for the lack of ACP (Douglas & Brown, 2002).

The residents who were capable of expressing themselves and who participated in the study reported that they would not want everything to be done simply to prolong the physical aspect part of life. The nurses did not believe that it was right to sustain the life of someone at all costs without quality of life and they would not want it for themselves. It was the family members who held strongly to the culture of **'Do everything'** to maintain the life of their loved ones. Interestingly, these families would not want it for themselves just for the sake of maintaining their life either. These family members wanted to do everything because they might believe a) that doing everything was what was best for the older person; b) that ACP and ACD would limit the care at the end of life, which would eventually prevent them from 'doing everything and doing their best' for their loved ones. It indicates that there is a need to clarify what was the best not for the family but for the older person. A concern that **ACP will shorten life or minimise the care that they deserve and doing ACP is seen as giving up** was evident. This finding is significant, as current literature does not include the above concern.

The researcher now discusses how ACP has contributed to the changes in these cultures. In the study undertaken by Cartwright (2000), community members who wanted to have more options gave reasons ranging from experiences of the painful undignified deaths of family members to demanding control of the end stage of their own lives. In the study undertaken by Carr and Khodyakov (2007), five contributing factors to ACP activities were identified. These are recent hospitalisation, experience of the terrible death of a loved one,

having informal discussions prior to formal discussions, and educational resources and needs of the person. Fear of death and the physician as a decision-maker were negatively correlated to the involvement in ACP activities.

In the current study, first of all, the culture of ‘Don’t go there’ was changed to ‘Go there and discuss it’ because the participants found that ACP was not about how soon and/or how the person was going to die, but about **having discussions** on how an individual lived life, what s/he valued, how the person made decisions in the past, what the person saw as a good life. The participants realised that the discussion in ACP was not simply about death, which people were scared of as they had no control over it. However, it was about having more choices and controls in what end-of-life care options they had, whether they would want it or not, and what the consequences of having or not having the treatments would be. ACP provided them with the chance to recollect, reflect and compose themselves by talking through the issues within themselves, with their family members, and with health-care professionals including nurses. The benefits of having this discussion through ACP became evident when the resident had an episode of acute illness and the ‘end-of-life care’ wishes were respected. The families appreciated it when the ACP and POT did not jinx the death of the loved one but promoted comfort and dignity at the end of life.

Another reason for the change of culture of ‘Don’t go there’ occurred as a result of the **impact of past experience with death and dying**. Morton did want to discuss and plan his own death and dying process after he observed the horrible dying process of his sister. Jill, who had experienced her own near-death, was comfortable discussing end-of-life care options. Freddy, Ray, Tess, Laura, Krys and Suzie clearly made their point that the life that their loved ones wanted was not fulfilled unless they did ‘go there’ and discussed the issues. The majority of participants (Freddy, Ray, Carla, Heather, Kyma, Rita, Wilma, Tess, Rosa, Katie, Katrina, Theo, Bev, Laura, Milson, Krys, Suzie and Hanna) were prompted by the experience of the dying process of their loved ones and have begun ACP processes by discussing the issues with their family members. There was a new culture of ‘Go there and discuss it’ or ‘discussion, discussion, and discussion’. This new culture was clearly noted in the family members and nurses who participated in the study.

Secondly, the change of culture of ‘Do everything’ occurred as a result of the **impact of past experience with death and dying**. For example, the horrible death of his sister had a huge impact on Morton. He did not want everything to be done simply for the sake of maintaining life. The culture of change from ‘Do everything’ to ‘Do what the person wants’ also resulted from the **impact of current experience with ACP**. It became apparent during the discussions that family members wanted to do everything not for their loved ones but for themselves. The participants came to the realisation that the life that their loved ones wanted was not fulfilled by doing everything, but by doing what the person wanted.

Another reason for the change of the culture of ‘Do everything’ was that ACP and ACD did not limit the care they deserved for quality of life but did minimise the care they did not wish, for quantity of life. For example, Laura was surprised and relieved to find that ACP did not limit the care to ‘NFR’ but opened all other options by exploring different levels of care that could be provided to her Aunt Mary. For some family members, it was a great relief to have hospital PACS and palliative care teams coming to the facilities, because it gave them the sense of utmost endeavour, that they were doing everything for the person. Theo was happy that he did not minimise the care provided to his sister Tia, but she was still offered specialist care from the hospital through ACP.

Another possible contributing factor to the change of culture would be the attitudes and experiences of nurses with death and dying in the long-term care facility. Growing consensus suggests that initiating ACDs correlated positively with the acceptance of approaching death, and negatively with the fear of death, death avoidance, and escaping the acceptance of death (Black, 2007; George, 2002; Hobart, 2001; Koenig, 2002; Tennstedt, 2002). One RN mentioned her own battle with the death of her father before she felt comfortable initiating discussions with family members in the facility. The RNs who participated in the study reported that their experience of dying processes and the horrible death of the residents in the facility prompted them to more openly discuss end-of-life care issues with the families. The nurses’ own beliefs and interpretation of the culture of death and dying were not investigated in depth in the current study, as it was beyond the scope of this project. However, the findings represent initial empirical grounds to further investigate the relationship between nurses’ attitudes towards and experiences with death with their ACP behaviour.

The outcomes of the cultural changes through ACP were significant compared to the outcomes of the absence of ACP which resulted in repetitive hospitalisation without improvement, a lonely and undignified death in hospital, and family conflict between one member who wants invasive and futile treatment, and another family member who wants what would have been best for their loved one.

### **Recommendations for nursing practice**

1. Nurses need to understand and promote ‘an individual’s autonomy in the social context’ in which the person developed self-entity, continuity, and adaptive skills for life changes.
2. It is essential for nurses to be aware of the underlying reasons for the culture of ‘Don’t go there’, and ‘Do everything’ in order to understand and support people who might be interested in ACP but misled.
3. Nurses need to promote the contributing factors (discussion, the impact of past experience with death and dying, the impact of current experience with ACP, having PACS and palliative teams from hospital) to the change in culture in order to maximise participation in ACP in RACFs.
4. Support services from hospitals such as PACS and palliative care teams are imperative to give family members sense of fulfilment of their duty of care and should be involved in ACP in RACFs.

### **Research Question 3: How do residents, family members and RNs perceive their experience with ACP in RACFs?**

Attempts were made to understand attitudes and knowledge toward the end-of-life decision-making of older people, family members, doctors, nurses and other interdisciplinary groups (Blondeau et al., 1998; Cartwright et al., 1997; Steinberg et al., 1997; Steinhauer et al., 2000; Thompson, Barbour & Schwartz, 2003). Studies have evaluated the physicians’ attitudes and approaches to end-of-life care treatments (Davidson et al., 1989; Schiff et al., 2006; Schmidt et al., 2004; Smith et al., 2006; Waddell et al., 1996). There is only one study (Scherer et al., 2006) specifically focused on nurses’ knowledge, attitudes and experiences with ACDs and end-of-life decision-making, although the study examined

critical care nurses. Frank et al. (2003), Schiff, Rajkumar and Bulpitt (2000), and High (1993) examined views of older people on ACDs. The review of those studies concluded that all participant groups expressed positive attitudes towards ACDs and end-of-life decision-making and would like to be involved, although the perceptions of quality, preferences in treatments, and timing of discussion varied between the groups. The foci of those studies were mainly on the characteristics, determining factors, and intervention strategies (a) to ease the approach to initiate ACDs, (b) to improve/increase documentation of ACDs, (c) to predict preferences of treatment options.

However, the research aimed at understanding the experiences of people who participated in ACP and documented ACDs is limited. In the current study, the researcher attempted to reveal the qualitative aspects of the experience of residents, families, and RNs with ACP and ACD in RACFs. It was identified that the participants' experiences were expressed in unpleasant, hostile and negative words. However, those emotions and concerns were transformed to more stable, amenable, and positive attitudes and feelings in the end. The factors that enhanced or inhibited the transition have been described in Chapter 5. In the following discussion, the researcher focuses on the significance that each group of people experienced, and what it indicated to nurses and for nursing practice.

#### **6.1.6 Gerotranscendence by residents, families and the RNs**

Surprisingly, the residents did not report any negative feelings about ACP but expressed satisfaction with the processes and the outcomes of ACP. Whilst the families were hesitant to discuss this and nurses were reluctant to initiate end-of-life care wishes, the residents appreciated the chance to express themselves. The residents were not afraid of discussing end-of-life care options with the expert nurse. In fact, they were very open, accepting, appreciative, responsible, content, calm, altruistic, surrendering and comfortable in talking about values in life, coping strategies for crises in life, and end-of-life care preferences for the future. This finding is consistent with the findings from the study undertaken by Bickerstaff, Grasser and McCabe (2003). The authors interviewed 95 residents about life in a long-term care facility and what behaviours helped keep them as healthy as possible while in the facility. Acceptance of life in the past, present, or future, and acceptance of physical condition were often mentioned. Contentment with oneself, finding happiness within oneself, and taking responsibility for oneself were other recurrent themes that emerged.

The ability to help others was a frequently reported theme for even for the most physically impaired residents. The residents in this study were also satisfied with themselves and with the life they had had despite the decline in health, functioning and social interaction.

Those positive attitudes, feelings and emotions experienced in ACP are underpinned in the concept of '**transcendence**' which emerged through the desire to go beyond the self, and to expand self-boundaries and life perspectives. Transcendence integrates "aspects of belonging, connecting, giving life, holding commitments, struggling with and surrendering ego, turning inward and becoming free" (Forbes, 1994. p, 267). Tornstam (1994, 1997, 1999/2000) theorised about gerotranscendence in that human aging brings about a general potential for a shift in perspective from the material world to the cosmic, and concurrent with that, an increasing life satisfaction. According to Tornstam (1999/2000), the characteristics of individuals with a higher degree of gerotranscendence are that they a) have high degrees of life satisfaction, b) engage in self-controlled social activity, c) experience satisfaction with self-selected social activities, d) demonstrate complex and active coping patterns, and e) have accelerated development of gerotranscendence fomented by life crises. The residents demonstrated these characteristics of gerotranscendence. For example, the residents were invited to reflect and explore (introspected) their mind, feelings, thoughts and views on themselves, significant others, life, and community as a whole (turning inward). They believed that they had a good life (life satisfaction) and rendered resources for better use (altruistic, giving life). It was natural for them to surrender themselves to others when they did not see any point in prolonging life any longer than they wanted (surrendering ego). ACP not only promoted autonomy and control but it also led a different level of their entity. The persons made decisions or statements for end-of-life care through ACP but also reflected and transcended their lives.

Whilst the residents described their experience with ACP as satisfactory and positive, the families' experience was more traumatic than the residents'. The families were puzzled, irrational, confronted, sorrowful and resentful because they were experiencing grief due to the loss of their loved one to dementia, and overwhelmed by the nature and extent of the decisions they had to make. Interestingly, the families of those residents who were not capable of expressing themselves recognised some of the characteristics of gerotranscendence when they looked into the life of their loved ones. The family members reported that a) mum/dad had a good life (life satisfaction), hence the resources should not

be used to prolong the kind of life that mum/dad would not have wanted but should be used to save those whose life prospects are longer and higher than mum's or dad's (surrendering ego and going beyond the self), b) mum or dad would never have liked where they were now (turning inward), c) there is no point prolonging suffering (surrendering), and d) they looked for support and confirmation from family members and nurses (back-up, connecting, belonging). These attributes have become the major motivational forces and comforting factors for proceeding with ACP and enhanced those negative attitudes and feelings to those of a more positive and satisfactory nature in the end.

However, nurses' concern that they might upset older people and family by talking about end-of-life care options, death and dying indicates that they were not aware of the residents' experience of gerotranscendence. This is consistent with the literature. Wadensten and Carlsson (2001) wondered if nurses recognised signs of gerotranscendence and how they were interpreted. In their study, nurses did recognise these signs (declining interest in social activity, alterations in perspectives of time, space, life and death, increased life satisfaction) occurring in many old people but saw them as evidence of aging or pathologic conditions rather than a natural developmental process of transcendence. It suggests that specific attributes of gerotranscendence need to be articulated more clearly to the nurses if they are to help older people and families experience gerotranscendence.

### 6.1.7 'Do it yourself'

Another possible explanation for the residents' positive attitudes and feelings experienced with ACP was that it may be easier, simpler, and more clear 'if you **do it yourself** than leave it to someone else to do it for you' as Jill, one of the residents mentioned. This is not surprising, as Steihauser et al. (2000) found that it was inappropriate and inaccurate for families, and doctors to represent what the older person would or would not have wanted. They surveyed nearly 1,500 people, including seriously ill patients, recently bereaved families, physicians, nurses, social workers, chaplains, and hospice volunteers to determine the factors considered important at the end of life. 'Being mentally aware' was considered to be important by 92 per cent of the patients, whilst only 65 per cent of physicians believed so. For the majority of the patients (88 per cent), being able to help others was important at the end of life, but surprisingly only 44 per cent of physicians agreed that this was important. Whilst it was important for the patients (88 per cent) not to be a burden to

society, only 44 per cent of physicians rated this as important. In the current study, for some participants, it was difficult to best represent what they thought would be wanted by the older person because they genuinely did not know what the person would have wanted. For others it was hard because of the perceived inappropriateness, emotions, grief and the guilt involved in discussing end-of-life care treatments and because of the fact that the consequences of the decisions might be the death of their loved one. This indicates that nurses should encourage the older person to think and discuss their choices while s/he is still capable of expressing her/himself. Nurses should be aware of one of the significant findings of Steinhauser et al. (2000), that whereas physicians tend to focus on physical aspects, patients and families tend to view the end of life with broader psychosocial and spiritual meanings shaped by a lifetime of experiences.

The frustrations, anger and negative feelings that the RNs experienced in ACP were derived mostly from the families' unrealistic expectations, abandoning the person in a vain situation, lack of commitment in planning for end-of-life care, denial, and demanding futile/abusive/burdensome treatments against nurses' professional and personal beliefs of what was best for the older person. The RNs' experience with ACP was more related to seeking justifications for ACP from personal, legal and ethical perspectives. For example, they justified their participation in ACP because ACP was not illegal, as it was different from euthanasia and assisted suicide. They accepted the concept of ACP because it was ethical giving the residents' and families' the right to make autonomous decisions with regard to end-of-life care. They also experienced personal satisfaction as they were able to deliver more person-centred care, maintaining the older person as pain-free, and promote dignity and comfort. They were relieved that they had directives written as a result of extensive and comprehensive discussions, hence the responsibility was taken off from their shoulders. Given that ACP was a new challenge for most of the RNs, it was not surprising that their experience with ACP was limited to trying to increase their own level of understanding of the concept of ACP rather than being actively engaged in residents' and families' transition processes. For example, the RNs were not involved in helping residents search for the essence of being, maintain continuity, and achieve transcendence, which are all of great importance to residents and families in ACP. As Hall, Schroder and Weaver (2002) found in their study, the roles of nurses were limited to informing residents and relatives about their rights to express their wishes in advance.



Another interesting finding in the experiences of the participants with ACP was a concern that was commonly mentioned by the residents, family members, and nurses that the wishes written in ACDs or POT might not be followed up by family members, doctors, or nurses, for whatever reasons. The residents were concerned that doctors might override their preferences, or a family member might misrepresent their preferences. Family members who documented POT for their loved ones expressed strong ambivalence between what they wanted to do for themselves and what they needed to do for their loved ones. Nurses were apprehensive of residents' wishes and preferences being not respected by any of the personnel such as family, GP, specialist, or after-hours doctors involved in the care. This finding is consistent with the literature. As shown in early studies, ACDs created in the long-term care setting are often cast aside when the resident is transferred to an acute hospital (Danis, 1994). Physicians may then refuse to follow ACDs because of concerns about litigation (Cartwright, 2000; Grant, 1993; Stewart, 2005), families incorporate their own beliefs or misinterpret the wishes of the older person (Perrin, 1997), and paternalism, the most frequent concern by both older people and their families, that is, unilateral decision-making not in accord with the person's stated wishes or value system might also occur (Gerber, 1995; Steinberg et al., 1997; Waddell et al., 1996). The above concern requires careful but full attention. It indicates how important it is for everyone involved needing to reach agreement, achieve acceptance, and take concerted action. It is also imperative that there is a system that promotes shared understanding about ACP and ACD/POT in the hospital and RACFs, for example, the staff in A & E, palliative care, PACS team, specialists, GPs, and after-hours doctors, so that the written end-of-life care wishes are not violated. It is apparent that the whole process of ACP will become a waste of time and effort unless it is agreed upon, shared, and supported by everyone involved.

#### **Recommendations for nursing practice**

1. Nurses should encourage the older person to think about and discuss her/his wishes while s/he is still capable of expressing her/himself with regard to end-of-life care options, as it is best if ACD is undertaken by the person.
2. Nurses are to recognise the fact that ACP is not limited to end-of-life care decision-making but embraces the concept of gerotranscendence which can help older people and their family members accept the course of nature and experience satisfaction in life towards and at the end of life.
3. Specific attributes of gerotranscendence need to be articulated more clearly to the

nurses and families if they are to help elderly people experience transcendence.

4. There should be a system to promote the wishes written in ACDs and POT being followed up by family members, doctors, and nurses. The system should be established between RACFs and hospitals to have consistent understanding about ACP and interpretation of ACDs/POT.

#### **Research Question 4: How is the scope of nursing practice perceived by the CNC and the RNs in ACP in RACFs?**

A profession's scope of practice is the full spectrum of roles, functions, activities and decision-making capacity that individuals within that profession are educated, competent and authorised to perform (ANMC, 2006). Apparently, the scope of nursing practice for ACP was not what the RNs were educated about and felt competent to perform with their basic qualifications, given that the ACP program was a pilot project when the expert nurse commenced implementation of ACP in RACFs in 2001. The scope of nursing practice revealed from the current study was the direct result of the dedication from the expert nurse, the managers, and the RNs to improve end-of-life care provided to the residents and their families in RACFs. The roles, functions, interventions, and clinical decision-making of the expert nurse, the managers and the RNs were all captured and depicted in Figures 5 – 2, 5 – 3 and 5 – 4 in Chapter 5. However, there were challenges that emerged from the data and that required further discussion. The researcher now discusses the challenges for nurses in ACP. Implications and recommendations are also drawn for the future scope of nursing practice in ACP in RACFs.

Given that nurses, more than any other professional group, responded very similarly to older people with regard to views on pain management, euthanasia, and physician-assisted suicide (Cartwright et al., 1997), that they wanted to be involved in end-of-life care discussions (Aranda & O'Connor, 1995; Cartwright et al., 1997) and have vigilant contact with patients in all settings (Kring, 2006), it is crucial to investigate the reasons for poor or less than optimal performance of nurses in ACP and implement strategies for improvement.

### 6.1.8 Boundaries, discrepancies and a shift of responsibility in roles and functions

Each group of nurses has made a distinctive contribution to the implementation and practice of ACP in RACFs. However, the data revealed a strong suggestion that the **boundaries** for roles and functions of each group of nurses (the expert nurse, the managers, and the RNs) were vague and needed further development. There was a **discrepancy** between what they expected each other to do and what they actually did in ACP. It was also noted that there was a **shift of responsibility and lack of communication** between the expert nurse, the managers, and the RNs. The expert nurse believed that ACP from initiation and discussion to completion of ACD or POT was practised by the managers and the RNs within their own facility whilst, in fact, the ACP process was initiated by the managers but did not proceed to discussion and documentation of ACD/POT without the participation and contribution of the expert nurse. The managers expected that the RNs should take a greater part in initiation and discussion of end-of-life care options as they were the first in line, providing hands-on care. The RNs believed that managers should do more than raise the issue of end-of-life care to the residents and families. These expectations are unspoken, unaccepted and unnoted within themselves. This is consistent with the findings of Hall, Schroder and Weaver (2002), which showed that the role of nurses in end-of-life care decision-making is not well-defined. However, they found that nurses have roles were more apparent in documenting issues and care plans, providing symptom management, supporting families, and communicating with other health-care team members in relation to end-of-life care. Scherer et al. (2006) also found that few studies are available on nurses' involvement in end-of-life decision-making. It is only recently that Shanley and Wall (2004) proposed a number of roles that nurses can play in promoting and facilitating ACP, these are communication facilitator, risk identifier, emotional supporter, advocate, health-care agenda-setter, educator, and researcher. Among these roles, Seal (2007) emphasised the role of advocate in upholding patients' end-of-life care wishes.

The roles and functions of nurses in ACP in the Nursing Roles and Functions Model developed in this study captured most of the aspects discussed in the literature. The significance of the Model lies in that it can be used as a framework to guide nurses in relation to where they stand and what they do in ACP in RACFs. The applications of elements of the Nursing Brokerage and Nursing Roles and Functions Models reveal not

only the nature and extent of nurses' roles, functions and activities involved in ACP, but also the blueprint for future growth. The Nursing Roles and Functions Model provides nurses with not only what the nurses were doing in ACP currently, but also how they can expand nursing activities, particularly for the RNs in the future. For example, the majority of functions were performed by the expert nurse, however, the RNs themselves can expand and develop their roles and functions to a higher level and closer to that of the expert nurses.

### 6.1.9 Lack of time, knowledge, skills, experience, and confidence

Brown et al. (2005) questioned whether nurses were well informed about this complex area of the law, ethics and practice, as little is known about the role of nurses in relation to end-of-life decisions. Initially, the RNs' roles and functions in ACP within the facility were minimal. As far as the RNs were concerned, ACP was about documenting ACDs or POT by the residents or family members with the help of the expert nurse in a case conference organised by the managers. They just followed the written wishes when the time came. It needed an investigation on why the RNs' involvement in ACP was limited and whether it required expansion. One of the reasons identified was that the RNs on the floor were not invited to initiate end-of-life care conversations with residents or family members. The RNs were not able to or allowed to leave the floor to attend the lengthy and serial discussions, given the **lack of time**. This finding is consistent with that of Scherer et al. (2006).

Another reason identified was that the RNs themselves were not fully appreciative of what ACPs and ACDs were. They could not define what ACD was, but believed it was similar to a 'palliative care order' to make residents comfortable and pain-free when imminent death was expected, without sending residents to hospital. Some RNs were aware of what ACP was but did not know how and what to do, due to **lack of knowledge, skills, experience and confidence**. These nurses are not alone, considering that more than half of nurses ( $n = 399$ ) in a study (Crego & Lipp, 1998) indicated that they did not have a good understanding of ACDs. In a more recent study conducted by Scherer et al. (2006), the mean knowledge score of 210 critical care nurses on various issues in ACDs was 59.3 percent. One RN refused to accept the nurses' roles in ACP because it belonged to doctors.

The consequences of the above challenges, when not addressed, are detrimental. Some residents' wishes expressed, such as 'I don't want to be a burden' or 'I have had enough', were not addressed or explored properly because it did not concern them and they did not know what to do from that point. The managers and the expert nurse wanted the RNs to be more active in initiating and discussing end-of-life care issues with residents and families, but there was a no system to support the RNs to leave the floor and to be more confident in communicating about ACP. Dissatisfaction with their job because of the inappropriateness of the end-of-life care delivered was also experienced by nurses (Seal, 2007).

Nevertheless, the RNs in this study expressed the strong desire to do more in ACP in RACFs and this finding is consistent with Cartwright's study (2000). ANMC welcomes the RNs' passion to be involved in ACP. It is believed that ACP will fulfil nurses' advocacy role by providing both the framework and the skills for nurses to hold a discussion about end-of-lifecare (ANMC, 2006). To practise within the full scope of practice of the profession will require individuals updating or increasing their knowledge, skills and competence (ANMC, 2006). Brown et al. (2005) agree that there is a need for educating the nursing profession, particularly those working in aged care facilities about the rights of individuals and the relevant legislation.

There is a need and demand to expand or fully recognise and utilise the roles and functions for the RNs in RACFs. The RNs in RACFs need and want to be independent practitioners of ACP in initiation, discussion, completion and coordination of support services for end-of-life care. It is recommended that the Nursing Roles and Functions Model can be used as a framework to educate for amplification of the scope of practice of the RNs for ACP. The Nursing Brokerage Model can be used to develop the level of knowledge, skills, and expertise required of the RNs in ACP. There should be a system to support this move in facilities and the following suggestion could be a starting point.

#### **6.1.10 Designating and delegating**

Commitment from the managerial level to the implementation and practice of ACP was essential. Although the literature is silent on the roles of the managerial level in ACP, the

expert nurse in this study pointed out that the managers who demonstrated leadership and provided support to the RNs had inspired greater levels of motivation and participation from the RNs, which was also key to success in ACP implementation in RACFs. The Models developed in this study suggest that the managers' roles and functions can be extended to best support the RNs by **designating and delegating** a champion nurse in each facility. This suggestion is justified by the fact that the managers would only initiate the discussion on admission and informs the family members about the ACP available. However, they believed that they did not have the time and expertise to facilitate a resident or a family member to complete the ACD or POT. It was not until the expert nurse facilitated critical discussion that the ACD or POT was documented. The need for a designated person with expert knowledge and skills in ACP available in the facility was supported in the comments by the nurses that 'we need to clone her (the CNC)', and 'we always refer to her (CNC)'.

Whilst the managers made it clear that they did not have the time and expertise to get involved in critical discussion processes, the expert nurse believed that the managers and the RNs were able to fully perform their roles and functions as expected in initiation, discussion, and completion of ACDs or POTs, as they were given in-service education sessions about consent, the *Guardianship Act*, substitute decision-making, ACP, and ACDs. However, it is important to note that neither the managers nor the RNs had been educated to perform the comprehensive and extensive discussion process that the expert nurse used, and that this was the most critical part of the ACP process. In addition, the high turnover of RNs in RACFs and absence of intensive training of RNs in initiation, discussion, and completion of ACDs and POTs also have a detrimental effect on the levels of knowledge, skills and competence of the RNs in ACP. The idea of that the expert nurse, who they thought would take the ultimate responsibility in helping the older person and the family member document ACDs or POT in ACP, was not a realistic option as the expert nurse covers a large geographical area and ACP should be offered to every resident in the facility.

Therefore, it was suggested that one designated person become a champion who has expertise in ACP and skills in communication, psychomotor skills, the promotion of therapeutic relationships, leadership, and critical thinking. These elements of quality care should be readily available for application to the matters in related to ACP and ACD in each facility. The champion can also provide consistent in-service education sessions to the

RNs and others, despite the high turnover of staff members in the facility. The managers have a role in creating and supporting the designated person delegating the expert nurse in each facility. Shifting responsibility first to the resident and then to the family does not diminish but increases the extent and impact of the role of the nurse in ACP.

#### **Recommendations for nursing practice**

1. The RNs' roles and functions in ACP in RACFs were not well defined and are minimal developed. The Nursing Roles and Functions Model can be used as a framework to guide RNs in what was expected of them in ACP and to encourage them to expand their scope of practice.
2. Consistent with the literature, it was evident that the RNs in this study lacked knowledge, skills, experience and confidence in initiation, discussion, completion and coordination of support services for end-of-life care. The Nursing Brokerage Model can be used to guide nurses to be more independent practitioners of ACP.
3. Another challenge that nurses encountered was lack of time to participate and be involved in multiple lengthy discussions, which was an integral part of the ACP process. There should be a system from the managerial and organisational levels to support and resolve this challenge in the facilities. It was suggested that **one designated person** be a champion with expertise in ACP and skills in communication, psychomotor skills, promotion of therapeutic relationships, leadership, and capacity for critical thinking, should be readily available for matters in relation to ACP and ACD in each facility. The champion can also provide consistent in-service education sessions to the RNs and other despite the high turnover of staff members in the facility.

## **6.2 Limitations of the study**

Whilst the research was meaningful in its purpose of describing the phenomenon of ACP in RACFs, the researcher must acknowledge that every research project has its limitations and should be open to critique. One limitation in the present study would arise from the nature of qualitative research methods. The researcher, as a research instrument has the potential to contribute to serious subjectivity in the findings of the research. The researcher positioned herself in the study where she believed that the situations, conversations or activities were relevant to the study. She interpreted and projected the images collected in her own way to describe the phenomenon. Whilst the researcher herself attempted to

increase the consistency and coherence throughout the research processes, she also adopted a strategy to minimise bias arising from subjectivity. The codes and themes that emerged were reviewed, challenged and reworded by supervisors, where appropriate, in order to allow different interpretations of the phenomenon and to seek the most adequate representation of the phenomenon.

The researcher was concerned that the use of an observation approach might affect the participants' behaviours and attitudes with regard to the study. Therefore, some strategies were taken to minimise this. The researcher appeared to be accepted as an insider because she joined in activities with residents and was not easily recognised as an intruder. The researcher did not shadow any one nursing staff member in particular in the facilities until she was accepted as an insider, which was determined by the unconcerned comments and activities by the staff. The researcher presented herself in a way that demonstrated the study aim was not to assess the staff's performances and behaviour, but rather to observe the situations and events relevant to the study in the context. The researcher did not create a pattern and regularity in her presence in each facility, hence minimising the staff's anticipation and opportunity to change their practice. The researcher ensured that the data collected not only reflected the contemporary but also retrospective practice of ACP by looking at the documents dating back to 2001.

The researcher attempted to observe all types of interactions between the residents, families, and nursing staff in the context, and to capture any activity relevant to the study. She observed nursing and other activities in bathrooms, toilets, the dining rooms, corridors, nurses' stations, the hairdresser's rooms, the lounges, gardens, kitchens, laundries, staff dining rooms, and the main entrances to each nursing home over three different shifts over a period of seven months. However, as it was not possible to be present in two places at the same time or three different sites, the researcher might have missed some situations which might have been significant to the study. Therefore, the researcher attempted to retrieve any event or situation missed from nursing staff's communication book, hand-overs, residents' nursing progress notes, and conversations with the staff who had regular full-time employment in each facility. The saturation and the depth of data confirmed the researcher that a longer period of observation would not have guaranteed additional information relevant to the study.



The study revealed that the process of ACP and the documentation of ACDs/POT involved diverse groups of people who wanted to act on behalf of an individual older persons with regard to end-of-lifecare decision-making. The study has included the residents, families and the RNs as participants. The Assistants in Nursing (AINs) who were the majority of the workforce in the Australian nursing-home context were excluded from the study. This decision was made after the preliminary work with the expert nurse before developing the full detailed research proposal, as it appeared that ACP did not concern the AINs at that stage. The researcher's insight was confirmed by the expert nurse supporting the decision to exclude the AINs from the study. Neither the GPs who have regular contact with the older person and who hold the responsibility to prescribe medications and hospitalisation, nor the staff from the PACS and palliative care teams were included as participants in the study, due to its aims and the time limit imposed on the researcher by the course requirement. Therefore, the findings of this study are limited to those experiences of the residents, families, the RNs and managers in RACFs.

According to Stake (2005), multiple perspectives from various participants and multiple sites for a case study provide the researcher with a greater possibility for generalisation and theorisation. Although the generalisation of the findings in the study is open to question due to the small sample size, the saturation of the findings, which arose from three different groups of participants in three different RACFs has strengthened its generalisability. The perceptions and experiences of the participants from three sites were remarkably similar, despite the differences in the mission statements and values between the organisations. As far as the small sample size is concerned, the nature and purpose of the qualitative methods, which aimed to describe the phenomenon and add new knowledge to promote discussion and debate, justified the total number of participants interviewed. Despite the small sample size, the strength of the study lies in the discovery of raw patterns in the context and the negation of questions or hypotheses that can be tested in further research (Leininger, 1985).

### **6.3 Recommendations for further research**

The lack of discussion about and the practice of ACP in Australian health-care settings has impeded the chance to retain the autonomy of individual and family members in decision-making at the end of life. Health professionals doubted whether ACP was practised at all in

Australia and that there was little evidence to prove it would make any difference. Whilst there was a need for ACP and a call for nurse participation in RACFs, it was evident that there were significant deficits in knowledge about the ACP and the use of ACDs. The researcher investigated how ACP was implemented by an expert nurse, what the outcomes were, what the residents, families, and RNs experienced, and what the scope of nursing practice was in three RACFs. The findings of the study have identified several issues that need to be examined through further research. On the basis of the findings and discussion, the researcher provides the following recommendations for further research.

The initiation of ACP and the discussion of ACDs did not occur until an older person's physical and functional health deteriorated, and frequent hospitalisation for futile medical intervention caused exhaustion and resentment for family members and health-care professionals in both the facilities and hospitals. It was evident that the outcomes and experiences of ACP were clearly positive for the participants in retaining autonomy, delivering person-centred care, and providing directions for nursing staff. The participants believed that every resident should be involved in ACP and commence discussions with regard to end-of-life care choices. However, the study revealed that not all residents and families wanted to proceed with ACP. Whilst the current research revealed why residents and families participated in ACP, the investigation was not able to expand its depth and breadth, as it was beyond the aims of the study, to determine why the majority of residents and families did not participate in ACP and have ACDs documented. Whilst there was a plethora of advice from the participants to take the right to make decisions for oneself while they are still able to 'do it yourself' rather than leaving it to someone else, there is no evidence for nurses to help people who still want to leave the decisions to others.

Searching for the answers to this question should start by investigating why not all residents and family members were offered ACP in facilities. It is also not known how many residents and families who were invited to the ACP processes refused the opportunity to be involved and, more importantly, why.

The current research only confirmed the culture of 'don't go there' and 'do everything' and the brief encounter of the change of these cultures. However, an in-depth understanding and scientific evidence of people's rejection of ACP and the use of ACDs will generate more efficient ways to approach our ageing population and their significant family

members. More efficient ways do not necessarily mean an increase in the participation in ACP and documentation of ACDs, but will identify strategies to help people who decide not to participate in ACP deal with end-of-life care decision-making, given that they would face the issues sooner or later, and that they are also entitled to experience the benefits of ACP and ACDs. Further research is needed that includes in-depth and qualitative discussions on the reasons for people rejecting involvement in ACP and to write directives while they are capable. This would initiate interesting debates among nurses who would need to seek alternative ways to help these people. But if nurses need to pursue ways of getting residents involved in ACP, nurses need strategies to help them, or these people's wishes will be negated.

As the study revealed, ACP does not simply focus on what treatment an individual does or does not want to have at the end of life. ACP is a way to continue the essence of one's being and to make the transition from an individualistic and materialistic view of life to a more altruistic and cosmic level in life, accompanying transcendence. The critical foci for nurses, therefore, were to determine what the essence of one's being means for each individual, how they capture the essence of being to qualify as continuity, how they enhance the experience of transcendence through ACP. Whilst the 'Values Clarification Worksheet', and 'Nursing Home Project Assessment Form' used in this study served for their purposes, these sets of tools should be seen as a first attempt at addressing the foci described above. Deeper knowledge about the theories of 'continuity' and 'transcendence' could result in the development of more elaborate tools. This suggestion does not disregard other theories that may have an impact on understanding ageing process towards the end of life and those that did not emerge in this study. Therefore, ongoing research is needed to expand the current understandings of one's redefinition of self and relationships with others, and develop better tools to assess and reflect one's fundamental existential issues in ACP. The knowledge and evidence generated through ongoing research in this area are essential for nursing profession if they are to ensure that the myths and misunderstandings about ACP and ACDs are to be overturned, and older people develop and achieve a sense of themselves and satisfaction with their life through ACP and ACDs. In addition, new levels of understanding about how older people see ageing and end-of-life care issues will open another door to nursing students about how they can contribute to the process of continuity and transcendence of older people and their family members.

ACP fostered the autonomy of an individual in health-care decision-making. It was noted that resident participants in the study clearly expressed their preferences on treatment options once they were explained and discussed, and wanted to make their own decisions. More interestingly, none of the residents who participated in the study documented directives that might hasten death or assist them to commit suicide. Rather, they valued the life they had, and pursued their own definition of quality of life through ACP to the very end stage of their life. This is contrasted with the apprehension and opposition expressed by politicians or religious persons who oppose legalisation of the right to refuse or withdraw medical treatments, believing that older people will misuse the legislation to hasten death because they are depressed and dissatisfied with their life. The researcher proposes arguments to counter the above opinions with the evidence revealed by the current study. There has not been a better time than now to discuss the legal and political aspects of end-of-life care decision-making for our ageing population in this country. However, it is not certain whether replication studies with a larger number of older participants would generate similar results.

Therefore, suggestions for further research include additional cross-cultural studies, using a large number of samples from different social and ethnic backgrounds in multiple areas, and further exploration of preferences on end-of-life care options. The result of additional studies with a larger sample will ignite the debate on the legalisation of the right to refuse or withdraw medical treatments and legislation that supports older people to take more responsibility for end-of-life care.

The practice of ACP has just begun in the Australian health-care context and the research to explore and examine the practice and outcomes of ACP is scant. It is not surprising that the demand for scientific evidence to guide ACP and ACDs has never been so high. However, this demand has not been met to date. The research undertaken by the researcher has added a small but valuable contribution to the body of knowledge in this area. The practice of ACP should be evidence-based, therefore suggestions that will promote more serious discussion and debate on ACP and ACDs in Australia have been made for future research.

The researcher concludes the thesis with the description of the montage of the phenomenon of ACP in the following.

#### 6.4 Conclusion and The Montage

Advance Care Planning, the phenomenon which is the focus of this case-study research is the process of having discussions about treatment preferences for, toward and at the end-of-life with older persons themselves, family members and health-care professionals. Advance Care Planning may or may not eventuate in documenting the expressed wishes by older persons in Advance Care Directives and by persons responsible in Plans Of Treatment. A variety of factors that have been the catalyst for a greater interest in Advance Care Planning and Advance Care Directives involve rapidly increasing health-care costs (Cartwright & Parker, 2004; Chochinov & Janson, 1998; Crego & Lipp, 1998; Folbrecht, 1997), the ageing population (Carr & Khodyakov, 2007; Cartwright & Parker, 2004; Chochinov & Janson, 1998; Mezey, Bottrell & Ramsey, 1996), new life-sustaining technologies (Crego & Lipp, 1998; Hopp, 2000; Meyer, 2000), increasing patient awareness about their rights and hence increased demands for autonomy (Cartwright & Parker, 2004; Johns, 1996; Perrin, 1997; Westley & Briggs, 2004), the increasing number of older people who do not have a relative or friend who can make care decisions for them (Mezey, Bottrell & Ramsey, 1996), and increasing litigation associated with the provision of health care (Chochinov & Janson, 1998; Jordens et al., 2005). It has been noted that the benefits of having end-of-life care wishes documented have been particularly made explicit on the older people in RACFs, as they often appear in the medical emergency department in hospitals because of the symptoms of multiple pathophysiological health breakdowns. In these episodes of care they are often diminished in their capacity to make decisions for themselves and, without 'directives', intervention may be contrary to their values.

However, with the absence of scientific evidence available on ACP and ACDs in RACFs, it was not formally known how ACP was practised and what the older people experienced with ACP. In the Australian context, it is questionable whether, and indeed why and how it is that the older population has availed themselves of this power to express their wishes regarding end of life and under what conditions they should be allowed to die. The reasoning underpinning or the factors that impact on residents' decision to execute Advance Care Directives needed to be investigated. Formal evidence on the practice of ACP and use of ACDs in RACFs was not readily available at the commencement of this study. Another issue closely related to the development of implementation of ACDs was the extent to which nurses were involved in ACP and the execution of ACDs in RACFs.

Therefore, the current case-study research has been timely and appropriate in that it contributes to existing knowledge on the implementation, practice and outcomes of ACP in relation to designing and modelling the scope of practice for nurses in RACFs.

The findings of the study support the propositions proposed in this case study as described in Chapter Four and Five, in that

- implementation and utilisation of the ACP service by the CNC in RACFs promoted autonomy of residents and family members and maintained dignity of the older person, and
- the data collected highlighted the advanced nature of nursing interventions in the implementation and utilisation of the ACP service by the CNC in RACFs, which in turn developed and expanded the scope of practice of the CNC and the RNs.

The significance of the findings of this case-study research of the phenomenon of ACP lies in the realisation of the need to expand the domain of research on to involve exploration of experiences of ‘successful dying’. The current study of the phenomenon of ACP has made a contribution to greater awareness of what constitutes ‘dying well’ and how it can be achieved, by generating ‘A nursing theory of successful dying/gerotranscendence in end of life through ACP’. Another significant outcome of the study is that it captured how the older people themselves see and approach their own ‘sense of self’ and that of others in later life, and that they accept dying and death.

A plethora of research on the ageing process and healthy ageing exists, and its contribution to knowledge and policy development for old people is not minimal. Theories of ageing address a range of foci on adaptation to physical and functional changes (Lazarus & DeLongis, 1983), keeping active (Havighurst, Neugarten & Tobin, 1968), disengagement (Cumming & Henry, 1961), successful ageing (Flood, 2005), continuity of ageing (Atchley, 1987, 1989, 2001), and self-transcendence (Reed, 1991a, 1991b). Being alive or living without elements of quality at the end of life is reported as painful and lonely (Cartwright, 2000).

Issues around how and when one should die have traditionally been understood and decided by doctors and have focused mainly on ‘sanctity of life’ (Cartwright, 2000; Connor et al., 2002). Despite increasing numbers of people with chronic conditions and multiple co-morbidities that require multidimensional aspects of care, the psychological, social, emotional, practical or transcendent human needs are frequently not addressed (Connor et al., 2002). ‘Dying well’ has not been a common interest of old people, family members, and health-care professionals. It is important to note that the concept of ‘good’ and ‘bad’ death has been explored from the palliative-care perspective only recently (Costello, 2006). Despite the emergence of the concept of palliative, determining what constitutes dying well and a dignified death is subjective, and a theory that explains and promotes ‘successful dying’ is clearly absent.

A nursing theory of gerotranscendence in end of life through ACP was developed through integration of (a) the presentation of images of participants’ stories (narratives providing descriptions, understandings, meanings, and interpretation), (b) the issues that emerged and were discussed from the images, (c) the new understandings of the phenomenon, and (d) the findings from the literature in relation to the findings from the research. The ‘montage’ of the elements within the phenomena of ACP in RACFs gained prominence in the articulation of the above four, as they were projected from different angles, proportions, size, colour, depth, position, location and content. In the montage different voices and points of view were represented. To aid in the development of the montage, a consistent framework was developed and used, for example, one incorporating the following illuminating questions,

- In what ways does this story/image/issue exemplify answers to the research questions consistent with the findings and literature?
- What are the elements/factors/agents that compose or constitute the montage?
- What are the potential positive or negative consequences of ACP?
- What are the relationships within the stories/images/issues identified that are consistent with the phenomenon of ACP?
- How and in what way are the stories/images/issues connected in relation to the phenomenon of ACP?

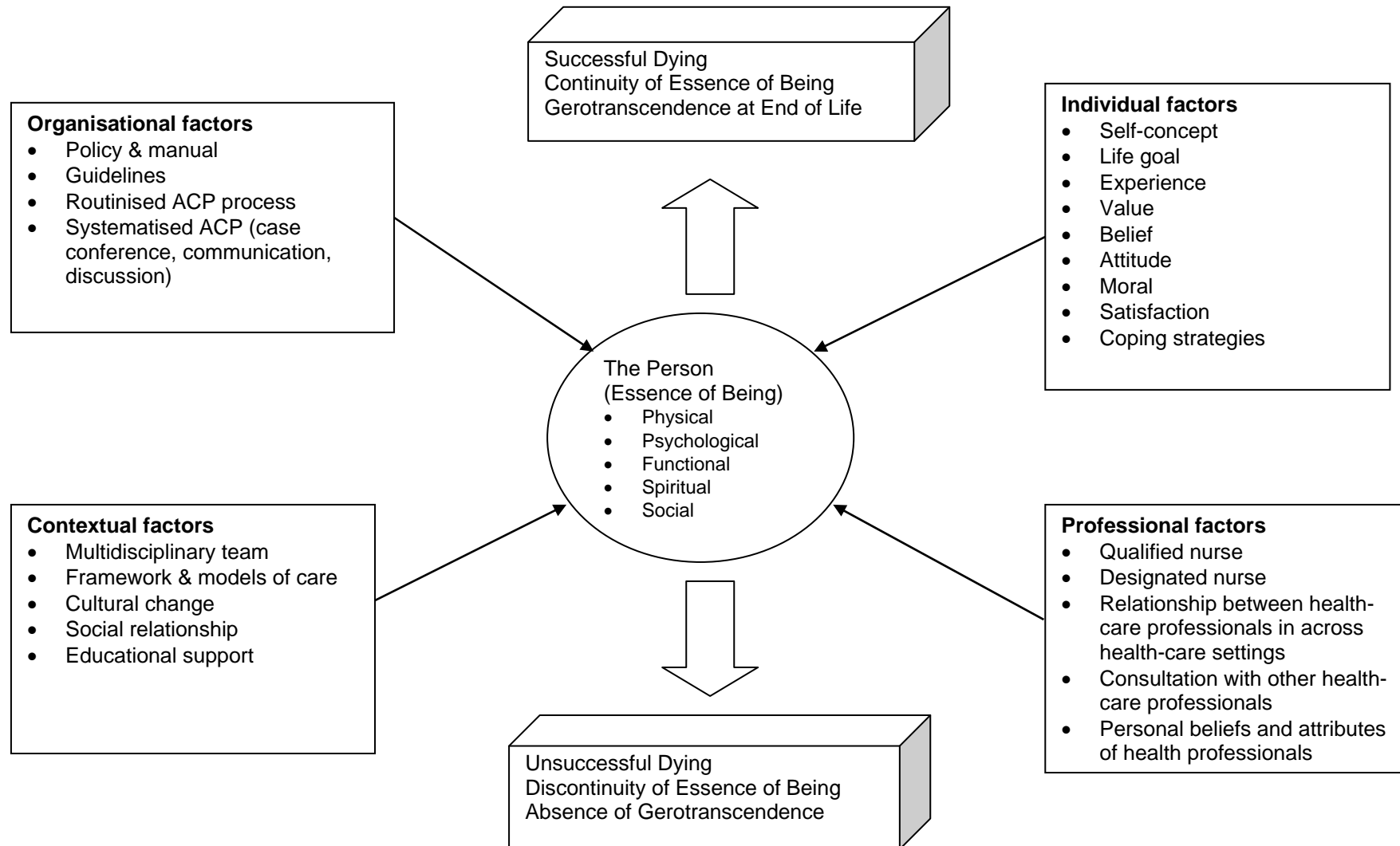
This allowed the researcher to integrate all the expressions of the participants' experiences with end-of-life decision-making and to create a new way to describe the phenomenon with deeper and wider understanding.

The misunderstandings and myths about ACP as euthanasia or assisted suicide were rectified by the CNC through the education during the implementation of ACP. Another view of ACP as a way of achieving a high level of execution of autonomy, mechanisms to maintain the health-care directives of an incapable person, and a palliative care order was found to be limited in sustainability and was challenged in this study. The study opened up a new level of understanding of the end-of-life care needs of older people and the meanings attached to ACP that have never been previously elaborated upon. The old people and families experienced a lot more than simply the task of documenting treatment preferences at the end of life or practising their right to make decisions in ACP. ACP facilitated the old person to continue to realise 'the essence of her/his being', to experience 'gerotranscendence' in end-of-life moments, and to die in a way consistent with 'the essence of her/his being' as they wished. This finding is consistent with one of the principles developed by Egan and Labyak (2001) that the last phase of life provides one with an opportunity for positive growth and development in the face of suffering. Byock (1996) explained that older people are often able to develop a sense of completion, to find meaning in their lives, to experience love of self and others, to say their goodbyes, and to surrender to the unknown.

Understanding and helping older people attend to these tasks in the way they choose should become an integrated approach by nurses to offer care that supports the older person and family to a self-determined life closure. However, old people will not automatically complete these tasks and reach a level of gerotranscendence. The nurses in RACFs, including the expert nurse, have expanded their horizons and stepped into this process of gerotranscendence within the end-of-life experiences. ACP has opened a new door for nurses to provide old people and their family with person-centred care towards and at the end of their lives. The researcher will now describe the elements that contribute to the theory of gerotranscendence in end-of-life experiences through ACP, which is depicted in Figure 6 – 1.



**Figure 6 – 1.**  
**‘A Nursing Theory of Gerotranscendence/Successful Dying through ACP’**



There are four integral factors that will lead to behaviours that contribute to successful dying, a level of continuity in essence of being, and the maintenance of experience consistent with gerotranscendence in end of life through ACP. These consist of individual, professional, organisational and contextual factors. The four factors are essential ingredients for nurses to facilitate people's experience of gerotranscendence towards and at the end of life and to prevent the person from being forced to discontinue the behaviours consistent with the essence of her/his being and to either prolong life or to face death in an undesired way. The person is the core element in the theory. The nature, process and outcomes are focused on who and what the person has been, and what the person wants in later life. In this regard, the theory described above shares the core concept described as 'person-centred care'. The Victorian Department of Human Services defines person-centred care as treatment and care provided by health services [that] places the person at the centre of their own care and considers the needs of the older person's carers (National Ageing Research Institute, 2006, p. 1). The overriding message in the concept is that

the service provider respects the contribution the service user can make to their own health such as their values, goals, past experience, and knowledge of their own health needs, and the service user respects the contribution the service provider can make, including their professional expertise and knowledge, information about the options available to the service user, and their values and experience (p. 1).

The person as a physical, psychological, functional, spiritual, and social being establishes her/his essence of being by containing and maintaining the inner structures that were developed over a lifetime of trials and errors, as previously discussed. The person uses these inner structures not only to adapt to the changes with ageing but also to maintain the 'essence of being' even toward and at the end of life. **Individual factors** are explored by an expert nurse in ACP and include how they see themselves (self-concept) and if they have achieved what they wanted to achieve in life (life goal). Experiences throughout one's lifetime and at the end of life, such as getting a job, marriage, divorce, health breakdown, ageing, repetitive hospitalisation and the death of close family or friends are explored in ACP, as it foretells how the person copes and maintains integrity and dignity in stressful situations. The person's values, beliefs, attitudes, moral and satisfaction in life are assessed in ACP, as it is important that they be maintained. Coping strategies developed over a lifetime have significance for each individual and need to be identified through ACP, as it guides nurses on how they can help the old people and family in accepting the changes which have occurred toward and at the end of life, and in particular in making end-of-life

decisions. Consistent with the findings of the study undertaken by Lambert et al. (2005), one can see that when the older person is given options the information is weighed on the basis of a complex mix of emotional, social and spiritual considerations. The relative importance of each of the factors cannot be predicted for individual person, as the descriptions of decision-making process and preferences indicate a rich and highly personal process. However, life experience and spiritual considerations were the most important sources in ACP and these two aspects also have significant impact on the family members when representing the old person.

Whether or not the person experiences gerotranscendence is influenced by the nature and extent to which health professionals serve as primary caregivers to the old person. **Professional factors** refer to the external human elements, other than the person, that contribute to gerotranscendence in end-of-life experiences. Professional factors include the roles of nurses and other health-care professionals, their potential for therapeutic relationships, and their personal beliefs and attributes. For example, nurses who demonstrate the capacity for therapeutic relationships through communication, psychomotor, leadership attributes, and critical thinking should be able to bring about and integrate inner structures of the individual relevant to ACP. Designated nurses with these qualities can facilitate and broker ACPs in each RACF. Relationships and consultations between health-care professionals in multidisciplinary teams generate a concerted effort in helping the older person maintain an essence of being and experience gerotranscendence. Like the older person's essence of being, the beliefs and attributes of health-care professionals are grounded in their own hopes and values about life as well as in values that are held in common by members of the profession. Nurses who hold the belief that each individual has the right to refuse or request treatments at the end of life encourage the older people and their family to have discussions and are themselves open to discussion. Support of older persons from qualified and designated nurses throughout the time necessary to complete their deliberations would lend a level of quality and compassion to care for older people that currently may not be present.

The processes and systems in an organisation are also important factors that impact upon the older person's gerotranscendence through ACP. **Organisational factors** include policy, manuals and guidelines which are in place for the staff in relation to ACP. Routinised processes for ACP in pre- and post- admission to facility contribute to equal

opportunity for all residents and families to participate in ACP and to ultimately experience gerotranscendence. Systematised processes in ACP for case conferences, discussions, and communication support individual and professional factors in leading the old person toward gerotranscendence at the end of life.

**Contextual factors** refer to the various sets of elements that surround ACP. The social context in which the person develops relationships with others such as family is an integral part of the experience of gerotranscendence in ACP. The multidisciplinary team involved impacts on the successful practice of ACP in respecting residents' wishes, whether these be 'no hospitalisation', 'NFR', or 'palliative care only'. The multidisciplinary team care does not mean one that is physician-directed and with each team member operating in her/his own professional silo. It means one that creates an end-of-life experience that is consistent with the person's values and goals for life closure. Each older person and family facing situations at the end of life does so in a unique way. Effective multidisciplinary teams do not attempt to impose a right way to die on an older person and family. The dimensions that the person and family feel are important to be identified, and care is designed to address these areas, which include the physical, interpersonal, internal, and the transcendent. The frameworks developed from this study for ACP would contribute to the implementation of ACP and guide nurses through the adaptation of functions as a new scope of practice expands. The cultural change which emerges as a result defeats the taboo of 'Don't go there', and 'Do everything' that impedes initiation of ACP and completion of ACDs. The strategies to induce the cultural changes are discussed and need to be taken to intervention stages. Empowerment and enablement of the older person and her/his family through education enhance progress toward gerotranscendence. Educational support for the staff interrelate to the professional factors (their own attitudes and values of) and organisational factors (discussion and communication).

The major elements of the theory of gerotranscendence in end-of-life situations are that the old person and their own care needs are at the centre. Their wishes are respected in a manner consistent with their self-concept, life goals, experiences, values, beliefs, attitudes, morals, satisfaction and coping strategies. The carers of the old person re-present over a 'person-centred care' needs within the boundaries of the closest social relationships built in a lifetime. Health-care professionals, in particular the nurse's contribution, are distinctive for their articulation of professional expertise, knowledge, skills, and commitment in ACP,

leading the old person into behaviours consistent with gerotranscendence in end-of-life episodes of care.

The elements of the theory of gerotranscendence also highlight the shared ownership of care needs between the old person, family and the nurses; accessibility and flexibility in the multidisciplinary team and their services; knowing the essence of the old persons from the perspective of the persons themselves or from their closest social relation; consideration of the attributes of the whole person; the importance of resources in organisations; and utilisation of various elements of the theoretical framework in context.

Some exemplars of situations in which gerotranscendence might flourish include those involving communicative, competent and enthusiastic staff; allowing the involvement of the person and families; accommodating the social nature of the autonomy of the person; providing opportunities for staff reflection on their values, beliefs and concerns; encouraging staff training and education in ACP and gerotranscendence; providing organisational support; commitment to an environment of mutual respect and trust.

The barriers to the encouragement and provision of behaviours consistent with gerotranscendence relate to the additional time required for delivery of ACP, dissolution of professional power; limitations in knowledge and skills of nursing staff in ACP; a lack of clarity around the concept; cultural taboos on death and dying; and a lack of commitment.

A plethora of research exists to identify and suggest strategies to promote the initiation of end-of-life discussion and to increase the completion of ACDs. Given that age, race, religion and educational level continue to be weak predictors of the completion of advance directives (Inman, 2002), the findings of the current study provide a new understanding of how directives were sought and what the outcomes were for older persons, families, and nurses. There is a need for nurses to pay closer attention to each person's decision-making processes. Increased vigilance to the factors influencing the decision-making processes will enable them to provide the best care possible to elderly residents of long-term care facilities as these difficult decisions are made (Lambert et al., 2005).

The factors affecting the experience of 'gerotranscendence' and decision-making described here are not intended to be an exclusive and conclusive representation of the factors

involved in ACP and ACDs. Rather, this study suggests a new framework to which health-care professionals may refer in their interactions with older people and in promoting 'dying well'.

There has been a call for ACP and ACDs in an era of consumer rights, cost-containment and an ageing population. The challenge given to the nursing profession is a formidable but compelling agenda for action. ACP provides old people and their family members with an opportunity not only to express their preferences for end-of-life care but also to respect their essence of being even toward and at the end of life. ACP and ACDs in RACFs project the scope of nursing practice as an expanded one in end-of-life care, and positive images of nurses' commitment and effort to meet the contemporary health-care needs of old people and their family members. The study reminds us that everyone deserves to die in a manner as well as or better than they had always lived, and offers the nursing profession a theoretical framework within which to commence, realise and build their levels of commitment.

## Epilogue

The images described in Chapter One became the major driving force for the researcher to develop this research project. The researcher now revisits those images and provides the readers with the details of the outcomes of each situation.

Mr Cho died in the middle of a chaotic situation with horrific pain arising from the ugliest family conflict. I was glad that the 'fight' was over for him and Mr Cho was allowed to die as he wished. However, I could not stop thinking about why Mr Cho had had to bear the horrific pain and suffering, and the loss of his dignity and integrity at the end of his life.

George died in the hospital. That was what I found when I came back to work a week later. Shirley came in and picked up his belongings. I felt that the way George died was not right and that something which should have been done had not been done for George. I was frustrated that I did not know what to do to make things better for him. I was horrified at how many people have to experience what George went through.

The researcher intended to alert readers of the dilemmas arising from people's impending death by projecting these two different images about the issues in end-of-life care decision-making, the varying capacity to make decisions, the involvement and nature of the roles of substitute decision-maker, consideration of aspects of quality of care at the end of life, simply allowing the person to die, the extent of person-centred care, and the importance, indeed necessity of written directives of treatment preferences, all now available to health-care professionals and their clientele.

## References

- Acts Amendment: Advance Health Care Planning Bill (2006). The Parliament of Western Australia.
- Advance Care Directive Association Inc. (2003). My health, my future, my choice. Annandale: Advance Care Directive Association Inc.
- Allen, R. S., DeLaine, S. R., Chaplin, W. F., Marson, D. C., Bourgeois, M. S., Dijkstra, K., & Burgio, L. D. (2003). Advance care planning in nursing homes: Correlates of capacity and possession of advance directives. The Gerontologist, 43(3), 309-317.
- Amen Long-Term Care Manual. (2002, July). Pain management and palliative care. (Version 1A). Sydney: Amen Long-Term Care.
- Andersen, B. M. (1978). A basic nurse-education curriculum evaluation project incorporating an investigation into the cognitive aspects of clinical judgment. Sydney: NSW College of Nursing.
- Andersen, B. M. (1991). Mapping the terrain of the discipline. In G. Gray & R. Pratt (Eds.). Towards a discipline of nursing (pp. 95-123). Melbourne: Churchill Livingstone.
- Anglicare. (2004, April). Advance care directives or plan of treatment protocol. Sydney: Anglicare.
- Aranda, S., & O'Connor, M. (1995). Euthanasia, nursing and care of the dying: Rethinking Kuhse and Singer. Australian Nursing Journal, 3(2), 18-21.
- Ashby, M., Wakefield, M., & Beilby, J. (1995). General practitioners' knowledge and use of Living Wills. British Medical Journal, 310(6974), 230.
- Atchley, R. C. (1987). Aging: Continuity and change. Belmont, California: Wadsworth Publishing Company.
- Atchley, R. C. (1989). A continuity theory of normal aging. The Gerontologist, 29, 183-190.
- Atchley, R. C. (2001). Continuity theory. In G. L. Maddox (Ed.), The encyclopedia of aging (pp. 246-248). New York: Springer Publishing Company.
- Australian Bureau of Statistics. (2006). Population Projections 1997-2051. Canberra: Australian Bureau of Statistics.
- Australian Government Department of Health and Ageing. (2003). Aged care in Australia. Canberra: Commonwealth of Australia.
- Australian Institute of Health and Welfare (AIHW). (2004). Australia's Health. Canberra: Australian Institute of Health and Welfare.
- Australian Nurses and Midwifery Council (ANMC) (2006). National Competency Standards for Registered Nurses. Canberra: ANMC.



- Axford, R. (1995). The context of nursing care delivery. In A. Nolan and L. Hazelton (Ed.), The practising nurse (pp. 95-131). Sydney: W. B. Saunders.
- Ball, S. C. (2006). Nurse – patient advocacy and the right to die. Journal of Psychosocial Nursing and Mental Health Services, 44(2), 36-42.
- Barta, K., & Neighbors, M. (1993). Nurses' knowledge of- and role in-patients' end-of-life decision-making. Trends in Health Care, Law & Ethics, 8(4), 50-52.
- Bartlett, R. (2007). 'You can get in alright but you can't get out': Social exclusion and men with dementia in nursing homes: Insights from a single case study. Quality in Ageing, 8(2), 16-26.
- Basile, C. (2002). Patient and community education in advance directives. Critical Care Nursing Clinics of North America, 14(2), 215-217.
- Beech, P., & Norman, I. J. (1995). Patients' perceptions of the quality of psychiatric nursing care: Findings from a small-scale descriptive study. Journal of Clinical Nursing, 4(2), 117-123.
- Beil-Hildebran, M. (2006). The implications of management by walking about: A case study of a German hospital. Leadership in Health Services, 19(4), i-xv.
- Bergen, A. (1992). Evaluating nursing care of the terminally ill in the community: A case study approach. International Journal of Nursing Studies, 29(1), 81-94.
- Bergen, A., & While, A. (2000). A case for case studies: Exploring the use of case study design in community nursing research. Journal of Advanced Nursing, 31, 926-934.
- Bickerstaff, K. A., Grasser, C. M., & McCabe, B. (2003). How elderly nursing home residents transcendence losses of later life. Holistic Nursing Practice, 17(3), 159-165.
- Biegler, P. C., Stewart, C., Savulescu, J., & Skene, L. (2000). Determining the validity of advance directives. Medical Journal of Australia, 172, 545-548.
- Black, K. (2007). Health care professionals' death attitudes, experiences, and advance directive communication behavior. Death Studies, 31(6), 563-572.
- Blackhall, L. J. (1987). Must we always use CPR? New England Journal of Medicine, 317,(20), 1281-1285.
- Blondeau, D., Valois, P., Keyserlingk, E., Herbert, M., & Lavoie, M. (1998). Comparison of patients' and health care professionals' attitudes towards advance directives. Journal of Medical Ethics, 24(5), 328-335.
- Board, N., Brennan, N., & Caplan, G. (2000). A randomised controlled trial of the costs of hospital as compared with hospital in the home for acute medical patients. Australian and New Zealand Journal of Public Health, 24(3), 305-311.
- Braam, A., B., Inge, B., van Tilburg, T., van der Ploeg, H., & Deeg, D. (2006). Cosmic

- transcendence and framework of meaning in life: Patterns among older adults in the Netherlands. Journal of Gerontology, 61B(3), S121-S128.
- Bradley, E., Walker, L., Blechner, B., & Wetle, T. (1997). Assessing capacity to participate in discussions of advance directives in nursing homes: Findings from a study of the Patient Self Determination Act. Journal of the American Geriatrics Society, 45(1), 79-83.
- Bravo, G., Dubois, M. F., & Paquet, M. (2003). Advance directives for health care and research: Prevalence and correlates. Alzheimer Disease and Associated Disorders, 17(4), 215-222.
- Brown, M., Grbich, C., Maddocks, I., Parker, D., Connellan, R. P., & Willis, E. (2005). Documenting end of life decisions in residential aged care facilities in South Australia. Australian and New Zealand Journal of Public Health, 29(1), 85-90.
- Burns, N., & Grove, S. K. (1995). Understanding nursing research. Philadelphia: WB Saunders.
- Byock, I. (1996). The nature of suffering and the nature of opportunity at the end of life. Clinics in Geriatric Medicine, 12(2), 237-252.
- Byrne, M. (2001). Critical incident technique as a qualitative research method. AORN Journal, 74(4), 536-539.
- Callahan, D. (1996). Controlling the costs of health care for the elderly – Fair means and foul. The New England Journal of Medicine, 335(10), 744-746.
- Cantor, M. D., & Pearlman, R. A. (2003). Advance care planning in long-term care facilities. Journal of the American Medical Directors Association, 4(2), 101-108.
- Caplan, G., Meller, A., Squires, B., Chan, S., & Willett, W. (2006). Advance care planning and hospital in the nursing home. Age and Ageing, 35(6), 581-585.
- Carr, D., & Khodyakov, D. (2007). End-of-life health care planning among young-old adults: An assessment of psychosocial influences. The Journals of Gerontology, 62B(2), S135-S141.
- Cartwright, C. (2000). End-of-life decision making: Practical and ethical issues for health professionals. Australasian Journal on Ageing, 19(2), 57-62.
- Cartwright, C. M. & Parker, M. H. (2004). Advance care planning and end of life decision making. Australian Family Physician, 33(10), 815-817, 819.
- Cartwright, C., Steinberg, M., Williams, G., Najman, J., & Williams, G. (1997). Issues of death and dying: The perspective of critical care nurses. Australian Critical Care, 10(3), 81-87.
- Chiarella, M. (1994). Interim guidelines on dying with dignity. Australian Confederation of Operating Room nurses, 7(2), 27-29.

- Chochinov, H., & Janson, K. (1998). Dying to pay: The cost of end-of-life care. Journal of Palliative Care, 14(4), 5-15.
- Clayton, J. M., Butow, P. N., & Tattersall, M. HN. (2005). When and how to initiate discussion about prognosis and end-of-life issues. Journal of Pain and Symptom Management, 30(2), 132-144.
- Clayton, J. M., Hancock, K. M., Butow, P. N., Tattersall, M. HN., & Currow, D. C. (2007). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. The Medical Journal of Australia, 186(12), S77-S108.
- Connor, S. R., Egan, K. A., Kwilosz, D. M., Larson, D. G., & Reese, D. J. (2002). Interdisciplinary approaches to assisting with end-of-life care and decision making. American Behavioral Scientist, 46(3), 340-356.
- Cook, D., Rocker, G., Marshall, J., Griffith, L., McDonald, E., & Guyatt, G. (2006). Levels of care in the intensive care unit: A research program. American Journal of Critical Care, 15(3), 269-278.
- Costello, J. (2006). Dying well: Nurses' experiences of 'good and bad' deaths in hospital. Journal of Advanced Nursing, 54(5), 594-601.
- Crawley, L., Marshall, P. A., Lo, B., & Koenig, B. A. (2002). Strategies for culturally effective end-of-life care. Annals of Internal Medicine, 136, 673-679.
- Crego, P. J. (1999). When, how, and why of advance directives: Tools for the cardiovascular nurse. Progress in Cardiovascular Nursing, 14(3), 92-96.
- Crego, P. J., & Lipp, E. J. (1998). Nurses' knowledge of advance directives. American Journal of Critical Care, 7(2), 218-223.
- Crookes, P., & Davies, S. (1998). Research into practice. Sydney: Bailliere Tindall.
- Cumming, E., & Henry, W. E. (1961). Growing old: The process of disengagement. New York: Basic Books.
- Curtis, J. R., Park, D. R., Krone, M. R., & Pearlman, R. A. (1995). Use of medical futility rationale in do-not-resuscitation orders. Journal of the American Medical Association, 273(2), 124-128.
- Danis, M. (1994). Following advance directives. The Hastings Centre Report, 24(6), S21-S23.
- Davidson, K. W., Hackler, C., Caradine, D. R., & McCord, R. S. (1989). Physicians' attitudes on advance directives. JAMA, 262(7), 2415-2419.
- Davis, G. (2004). Dying by inches. Sydney: NBN.
- Davitt, J. K., & Kaye, L. W. (1996). Supporting patient autonomy: Decision making in home health care. Social Work, 41(1), 41-50.

- Denzin, N. K. (1978). The research act. New York, McGraw & Hill.
- Denzin, N. K., & Lincoln, Y. S. (2005). The SAGE handbook of qualitative research. London: SAGE Publications.
- Department of Health. (April 2005). Chief executive bulletin: 264, 8-14, Department of Health. Retrieved July 4, 2007, from [http://www.dh.gov.uk/en/Publicationsandstatistics/Bulletins/Chiefexecutivebulletin/DH\\_4127021](http://www.dh.gov.uk/en/Publicationsandstatistics/Bulletins/Chiefexecutivebulletin/DH_4127021)
- DesRosiers, M., & Navin, P. (1997). Implementing effective staff education about advance directives. Journal of Nursing Staff Development, 13(3), 126-130.
- Diamond, E. L., Jernigan, J. A., Moseley, R. A., Messina, V., & McKeown, R. A. (1989). Decision-Making Ability and Advance Directive Preferences in Nursing Home Patients and Proxies. The Gerontologist, 29(5), 622-626.
- Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dressor, R., Fagerlin, A., Gready, M., Houts, R. M., Lockhart, L. K., & Zyzanski, S. (2001). Advance care directives as acts of communication: A randomised controlled trial. Archives of Internal Medicine, 161, 421-430.
- Douglas, R., & Brown, H. N. (2002). Patients' attitudes toward advance directives. Journal of Nursing Scholarship, 34(1), 61-65.
- Duffield, P. (1998). Advance directives in primary care. American Journal of Nursing, 98(4), 16CCC-DDD.
- Dunford, M., Donoghue, J., & Lazaris, M. (1999). Case presentation of nurse-managed noninvasive positive pressure ventilation in an acute ward setting. Heart & Lung: The Journal of Acute and Critical Care, 28(5), 348-351.
- Dunlap, R. (1997). Teaching advance directives: The why, when, and how. Journal of Gerontological Nursing, 23(12), 11-16, 54-55.
- Ebell, M. H. (1992). Prearrest predictors of survival following in-hospital cardiopulmonary resuscitation: A meta-analysis. The Journal of Family Practice, 34(5), 551-558.
- Egan, K. A., & Labyak, M. J. (2001). Hospice care: A model for quality end-of-life care. In B. R. Ferrell, & N. Coyle (Ed.), Textbook of palliative nursing (pp. 7-26). New York: Oxford University Press.
- Egan, M., & Kadushin, G. (1998). The social worker in the emerging field of home care: Professional activities and ethical concerns. Health & Social Work, 24(1), 43-55.
- Ejaz, F. K. (2000). The influence of religious and personal values on nursing home residents' attitudes toward life-sustaining treatments. Social work in Health Care, 32(2), 23-39.
- Elliot, D. (2003). Approaches to research. In Z. Schneider, D. Elliot, G. LoBiondo-Wood, & J. Haber (Eds.), Nursing research: Methods, critical appraisal and utilisation (pp.

21-37). Sydney: Mosby.

- Elpern, E. H., Barry, M. J., Stoeckle, J. D., Ettelson, L. M., & Emanuel, E. J. (1993). A preliminary investigation of opinions and behaviors regarding advance directives for medical care. American Journal of Critical Care, 2(2), 161-167.
- Emanuel, E. J., & Emanuel, L. L. (1990). Living wills: Past, present, and future. Journal of Clinical Ethics, 1(1), 9-19.
- Emanuel, L. L., Barry, M. J., Stoeckle, J. D., Ettelson, L. M., & Emanuel, E. J. (1991). Advance directives for medical care: A case for greater use. The New England Journal of Medicine, 324(13), 889-895.
- Fagerlin, A., Ditto, P. H., Hawkins, N.A., Schneider, C. E., & Smucker, W. D. (2002). The use of advance directives in end-of-life decision making. American Behavioral Scientist, 46(2), 268-283.
- Fassier, T., Lautrette, A., Ciroldi, M., & Azoulay, E. (2005). Care at the end of life in critically ill patients: The European perspective. Critical Care, 11(6), 616-623.
- Faunce, T. A. & Stewart, C. (2005). The Messiha and Schiavo cases: Third-party ethical and legal interventions in futile care disputes. The Medical Journal of Australia, 183(5), 261-263.
- Field, M., & Cassel, C. (1997). Approaching death: Improving care at the end of life. Washington, DC: Institutes of Medicine: National Academy Press.
- Fins, J. (1997). Advance directives and SUPPORT. Journal of American Geriatric Society, 45(4), 519-520.
- Flanagan, J. (1954). The critical incident technique. Psychological Bulletin, 51(4), 327-358.
- Flood, M. (2005). A mid-range nursing theory of successful aging. Journal of Theory Construction & Testing, 9(2), 35-39.
- Folbrecht, D. (1997). Separate and equal: Hospice and home health care. Home Health Care and Management Practice, 9(5), 1-9.
- Forbes, E. J. (1994). Spirituality, aging, and the community-dwelling caregiver and care recipient. Geriatric Nursing, 16(6), 297.
- Ford, S., Schofield, T., & Hope, T. (2003). What are the ingredients for a successful evidence-based patient choice consultation?: A qualitative study. Social Science and Medicine, 56(3), 589-602.
- Frank, R., & Campbell, M. (1996). The SUPPORT project and improving care for seriously ill patients. Journal of American Medical Association, 275(16), 1228-1229.
- Frank, C., Heyland, D. K., Chen, B., Farquhar, D., Myers, K., & Iwaasa, K. (2003). Determining resuscitation preferences of elderly inpatients: A review of the literature. Canadian Medical Association Journal, 169(8), 795-799.

- French Senate. (2004). Patients rights at the end of life in European countries. Comparative Law Study no. 139. Retrieved May 1, 2007, from <http://www.senat.fr/Ic/Ic139/Ic1390.html>
- Gage, B., & Dao, T. (2000). Medicare's hospice benefit: Use and expenditures 1996 cohort. Washington D. C: US. Department of Health and Human Services. Retrieved May 9, 2007 from <http://aspe.hhs.gov/daltcp/reports/96useexp.htm>
- Galambos, C. M. (1998). Preserving end-of-life autonomy: The Patient Self-Determination Act and the Uniform Health Care Decisions Act. Health & Social Work, 23(4), 275-281.
- Gamble, E. R., McDonald, P. J., & Lichstein, P. R. (1991). Knowledge, attitudes, and behavior of elderly persons regarding living wills. Archives of Internal Medicine, 151(2), 277-280.
- George, L. K. (2002). Research design in end-of-life research: State of science. The Gerontologist 42(Special Issue III), 86-98.
- Gerber, L. (1995). Ethics and caring: Cornerstones of nursing geriatric care management. Journal of Gerontological Nursing, 21(12), 15-19.
- Ghusn, H. F., Teasdale, T. A., & Jordan, D. (1997). Continuity of do-not resuscitate orders between hospital and nursing home settings. Journal of the American Geriatrics Society, 45(4), 465-469.
- Gilgun, J. F. (1994). A case for case studies in social work research. Social Work, 39, 371-380.
- Gillham, B. (2000). Case study research methods. London, Continuum.
- Gillick, M. R. (1995). A broader role for advance medical planning. Annals of Internal Medicine, 123(8), 621-624.
- Glen, S., & Waddington, K. (1998). Role transition from staff nurse to clinical nurse specialist: A case study. Journal of Clinical Nursing, 7(3), 283-290.
- Glick, K. L., MacKay, K. M., Balasingam, S., Dolan, K. R., & Casper-Isaac, S. (1998). Advance directives: Barriers to completion. Journal of New York State Nurses Association, 29, 4-8.
- Gordon, N. P., & Shade, S. B. (1999). Advance directives are more likely among seniors asked about end-of-life care preferences. Archives of Internal Medicine, 159(7), 701-704.
- Grant, A. (1993). Questions of life and death. The Canadian Nurse, 5, 31-34.
- Grbich, C. (2006). Communication and decision making for patients with end stage diseases in an acute setting. Contemporary Nurse, 23(1), 21-37.
- Greipp, M. (1996). The hospice choice: Ethical decision making. The American Journal of

- Hospice & Palliative Care, 13(5), 28-34.
- Hagerty, R. G., Butow, P. N., Ellis, P. A., Lobb, E. A., Pendlebury, S., Leighl, N., Goldstein, D., Lo, S. K., Tattersall, M. HN. (2004). Cancer patient preferences for communication of prognosis in the metastatic setting. Journal of Clinical Oncology, 22(9), 1721-1730.
- Hahn, M. E. (2003). Advance directives and patient – physician communication. Journal of the American Medical Association, 289, 96.
- Haisfield, M. E., McGuire, D. B., Krumm, S., Shore, A. D., Zabora, J., & Rubin, H. R. (1994). Patients' and healthcare providers' opinions regarding advance directives. Oncology Nursing Forum, 21(7), 1179-1187.
- Halcomb, E. J., Patterson, E., & Davidson, P. M. (2006). Evolution of practice nursing in Australia. Journal of Advance Nursing, 55(3), 376-390.
- Hall, P., Schroder, C., & Weaver, L. (2002). The last 49 hours of life in long-term care: A focused chart audit. Journal of the American Geriatrics Society, 50(3), 501-506.
- Hammersley, M. (1984). The researcher exposed. In R. Burgess (Ed.). The research process in educational settings: Ten case studies (pp. 39-67). London: Falmer Press.
- Havens, G, A, D. (2000). Differences in the execution/nonexecution of advance directives by community dwelling adults. Research in Nursing & Health, 23(4), 319-333.
- Havighurst, R. J., Neugarten, B. L., & Tobin, S. S. (1968). Disengagement and patterns of aging. In B. L. Neugarten (Ed.). Middle age and aging: A reader in social psychology (pp. 161-172). Chicago: University of Chicago Press.
- Hawkins, H., & Cartwright, C. (2000). Advance health care planning and the GP. Australian Family Physician, 29(7), 704-707.
- Haynor, P. (1998). Meeting the challenge of advance directives. American Journal of Nursing, 98(3), 26-32.
- Heffner, J., & Barbieri, C. (2001). Effects of advance care education in cardiovascular rehabilitation programs: A prospective randomised study. Journal of Cardiopulmonary Rehabilitation, 21(6), 387-391.
- Hewitt-Taylor, J. (2002). Case study: An approach to qualitative enquiry. Nursing Standard, 16, 33-37.
- High, D. M. (1993). Advance directives and the elderly: A study of intervention strategies to increase use. The Gerontologist, 33(3), 342-349.
- Hines, S. C., Glover, J. J., Holley, J. L., Babrow, A. S., Badzek, L. A., & Moss, A. H. (1999). Dialysis patients' preferences for family-based advance care planning. Annals of Internal Medicine, 130(10), 825-828.
- Hobart, K. R. (2001). Death and dying and the social work role. Journal of Gerontological

- Social Work, 36, 181-192.
- Hong, C. Y., & Lee, H. P. (1996). The advance directive: A review. Singapore Medical Journal, 37(4), 411-418.
- Hopp, F. (2000). Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: Results from a national study. The Gerontologist, 40(4), 449-457.
- Ingleton, C. (1998). Populations and samples: Identifying the boundaries of research. In P. Crookes., & S. Davies (Eds.). Research into practice: Essential skills for reading and applying research in nursing and health care (pp. 181-203). London: Bailliere Tindall.
- Inman, L. (2002). Advance directives: Why community-based older adults do not discuss their wishes. Journal of Gerontological Nursing, 28(9), 40-46.
- Jacobson, J. (2000). Advance medical directives. Nursing Case Management, 5(1), 26-31.
- Janofsky, J. S., & Rovner, B. W. (1993). Prevalence of advance directives and guardianship in nursing home patients. Journal of Geriatric Psychiatry & Neurology, 6(4), 214-216.
- Jarr, S., Henderson, M. L., & Henley, C. (1998). The registered nurse: Perceptions about advance directives. Journal of Nursing Care Quality, 12(6), 26-36.
- Johns, J. L. (1996). Advance directives and opportunities for nurses. Image: Journal of Nursing scholarship, 28(2), 149-153.
- Johnston, S. C., Pfeifer, M. P., & McNutt, R. (1995). The discussion about advance directives: Patient and physician opinions regarding when and how it should be conducted. Archives of Internal Medicine, 155, 1025-1030.
- Jordens, C., Little, M., Kerridge, I., & McPhee, J. (2005). From advance directives to advance care planning: Legal status, ethical rationales and a new research agenda. Internal Medicine Journal, 35, 563-566.
- Kadushin, G., & Egan, M. (2001). Ethical dilemmas in home health care: A social work perspective. Health & Social Work, 26(3), 136-149.
- Kaufman, S. R. (1993). Values as sources of the ageless self. In J. R. Kelly (Ed.). Activity and aging (pp. 17-24). Newbury Park: SAGE.
- Keatinge, D. (2002). Versatility and flexibility: Attributes of the critical incident technique in nursing research. Nursing & Health Sciences, 4(1-2), 33-39.
- Kemmis, S. (1980). The imagination of the case and the invention of the study. In H. Simons (Ed.). Towards a science of the singular (pp. 93-142). Norwick, UK: University of East Anglia, Centre for Applied Research in Education.
- Kemppainen, J. (2000). The critical incident technique and nursing care quality research.



- Journal of Advance Nursing, 32(5), 1264-1271.
- Kerridge, I. H., Pearson, S-A., Rolfe, I. E., & Lowe, M (1998). Decision making in CPR: Attitudes of hospital patients and health care professionals. Medical Journal of Australia, 169, 128-131.
- Kessel, A. S., & Meran, J. (1998). Advance directives in UK: Legal, ethical and practical considerations for doctors. British Journal of General Practice, 48, 1263-1266.
- Kirk, P., Kirk, I., & Kristjanson, L. J. (2004). What do patients receiving palliative care for cancer and their families want to be told? : A Canadian and Australian qualitative study. British Medical Journal, 328, 1343-1347.
- Kirmse, J. (1998). Aggressive implementation of advance directives. Critical Care Nursing Quarterly, 21(1), 83-89.
- Knaus, W. A., Wagner, D. P., Draper, E. A., Zimmerman, J. E., Bergner, M., Bastos, P. G., Sirio, C. A., Murphy, D. J., Lotring, T., Damiano, A., & Harrell, F. E. Jr. (1991). The APACHE III prognostic system risk prediction of hospital mortality for critically ill hospitalised adults. Chest, 100, 1619-1636.
- Koenig, H. G. (2002). A commentary: The role of religion and spirituality at the end of life. The Gerontologist, 42(Special Issue III), 20-23.
- Kring, D. L. (2006). An exploration of the good death. Advances in Nursing Science, 29(3), E12-E24.
- Krynski, M. D., Tymchuk, A. J., & Ouslander, J. G. (1994). How informed can consent be? New light on comprehension among elderly people making decisions about enteral tube feeding. The Gerontologist, 34(1), 36-43.
- Lambert, H. C., McColl, M. A., Gilbert, J., Wong, J., Murray, G., & Shortt, S. (2005). Factors affecting long-term care residents' decision-making processes as they formulate advance directives. The Gerontologist, 45(5), 626-633.
- LaPuma, J., Orentlicher, D., & Moss, R. J. (1991). Advance directives on admission: Clinical implications and analysis of the Patient Self-Determination Act of 1990. Journal of the American Medical Association, 266(3), 402-405.
- Larson, D. E. (1994). Resuscitation discussion experiences of patients hospitalised in a coronary care unit. Image: Journal of Nursing Scholarship, 23, 53-58.
- Lazarus, R. S., & DeLongis, A. (1983). Psychological stress and coping in aging. American Psychologist, 38(3), 245-254.
- Leininger, M. M. (1985). Qualitative research methods in nursing. Orlando: Grune & Stratton.
- Levinsky, N. G. (1990). 1824 as a Criterion for Rationing Health Care. The New England Journal of Medicine, 322(25), 1813-1816.

- Levinsky, N. (1996). The purpose of advance medical planning: Autonomy for patients or limitation of care. New England Journal of Medicine, 335(10), 741-743.
- Libbus, D. E., & Russell, C. (1995). Congruence of decisions between patients and their potential surrogates about life sustaining therapies. Image: Journal of Nursing scholarship, 27(2), 135-140.
- LoBiondo-Wood, G., & Haber, J. (1994). Nursing research, methods, critical appraisal and utilisation. St. Louis: Mosby.
- Mogg, M. (2006). Advance care planning: The right to decide. Australian Nursing Journal, 13(8), 18-21.
- Maben, J., & Macleod, C. (1997). The impact of Project 2000. Nursing Times, 93(35), 55-58.
- Mador, J. (2001). Advance care planning: Should we be discussing it with our patients? Australasian Journal on Ageing, 20(2), 89-91.
- Mansell, D., Kazis, L., Glantz, L., & Heeren, T. (1999). Roles of physicians, attorneys, and illness experience in advance directives. Southern Medical Journal, 92(2), 197-203.
- Markson, L., Clark, J., Glantz, L., Lamberton, V., Kern, D., & Stollerman, G. (1997). The Doctor's role in discussing advance preferences for end-of-life care: Perceptions of physicians practicing in the VA. Journal of American Geriatrics Society, 45(4), 399-406.
- Mason, E. J. (1994). How to write meaningful standards of care. Saratoga Springs: Delmar Publishers.
- Mathers, N., & Huang, Y. (1998). Evaluating methods for analysing data in published research. In P. Crookes., & S. Davies (Eds.). Research into practice: Essential skills for reading and applying research in nursing and health care (pp. 162-180). London: Bailliere Tindall.
- Mays, N., & Pope, C. (1995). Observational methods in health care settings. British Medical Journal, 311, 182-184.
- McGinty, J. (2006). Media statement: Laws to help people die with dignity. Perth, WA: Government of Western Australia.
- McMillan, M., P. Little, Bujack, E., & Conway, J. (2001). The contemporary scope of nursing practice and the implications for nursing education and practice. Canberra: Department of Education Science & Training.
- Meier, P., & Pugh, E. J. (1986). A case study: A viable approach to clinical research. Research in Nursing & Health, 9(3), 195-201.
- Metherell, M. (2004). Health costs to double in 40 years. Sydney Morning Herald: Sydney.
- Meyer, R. M. (2000). Using adult learning concepts to assist patients in completing advance

- directives. Journal of Continuing Education in Nursing, 31(4), 174-178.
- Mezey, M., Bottrell, M. M., & Ramsey, G. (1996). Advance directives protocol: Nurses helping to protect patient's rights. Geriatric Nursing, 17(5), 204-210.
- Mezey, M., Evans, L. K., Golub, Z. D., Murphy, E., & White, G. B. (1994). The patient self-determination act: Sources of concern for nurses. Nursing Outlook, 42(1), 30-37.
- Miles, S. H., Koepp, R., & Weber, E. P. (1996). Advance end-of-life treatment planning: A research review. Archives of Internal Medicine, 156, 1062-1068.
- Miller, F., & Fins, J. (1996). A proposal to restructure hospital care for dying patients. New England Journal of Medicine, 334(26), 1740-1742.
- Moeller, M. S. (2006). Indications for use of recombinant factor VIIa: A case study with implications for research. Journal of Trauma Nursing, 13(4), 190-192.
- Mogg, M. (2006). Advance care planning: The right to decide. Australian Nursing Journal, 13(8), 18-21.
- Molloy, D. W., Silberfeld, M., Darzins, P., Guyatt, G. H., Singer, P. A., Rush, B., Bedard, M., & Strang, D. (1996). Measuring capacity to complete an advance directive. Journal of the American Geriatrics Society, 44(6), 660-664.
- Molloy, D. W., Bedard, M., Guyatt, G., Patterson, C., North, J., Jubelius, R., Hassard, J., Willison, K., Darzins, P., & Harrison, C. (1997). Attitudes training issues and barriers for community nurses implementing an advance directive program. Perspectives, 21(1), 2-8.
- Molly, D. W., Guyatt, G. H., Russo, R., Goeree, R. et al. (2000). Systemic implementation of an advance directive program in nursing homes: A randomised controlled trial. JAMA, 283(11), 1437-1444.
- Morris, B. A., Van Niman, S. E., Perlin, T., Lucie, K. S., Vieth, J., Agricola, K., & McMurray, M. K. (1995). Healthcare professionals' accuracy in predicting patients' preferred code status. The Journal of Family Practice, 40(1), 41-44.
- Morse, J. (1991). Qualitative nursing research: A contemporary dialogue. Newbury Park, California: SAGE Publications.
- Morse, J. M., & Field, P. A. (1995). Qualitative research methods for health professionals. London: SAGE Publications.
- Munro, B. H. (1992). How many subjects are enough? Clinical Nurse Specialist, 6(1), 20.
- Murphy, D. J., Murray, A. M., Robinson, B. E., & Campion, E W. (1989). Outcomes of cardiopulmonary resuscitation in the elderly. Annals of Internal Medicine, 111(3), 199-205.
- Murphy, S. T., Palmer, J. M., Azen, S., Frank, G., Michel, V., & Blackhall, L. J. (1996).

- Ethnicity and advance directives. Journal of Law, Medicine, and Ethics, 24, 108-117.
- Murphy, C. P., Sweeney, M. A., & Chiriboga, D. (2000). An educational intervention for advance directives. Journal of Professional Nursing, 16(1), 21-30.
- Nair, B., Kerridge, I., Dobson, A., McPhee, J., & Saul, P. (2000). Advance care planning in residential care. Australian & New Zealand Journal of Medicine, 30(3), 339-343.
- National Ageing Research Institute. (2006). What is person-centred health care?: A literature review. Melbourne: The Victorian Government Department of Human Services.
- Nation Wise Products. (2002). The prepare-your-own enduring power of attorney and enduring guardianship. Virginia: Nation Wise Products Pty Ltd.
- Neuman, K., & Wade, L. (1999). Advance directives: The experience of health care professionals across the continuum of care. Social Work in Health Care, 28(3), 39-54.
- Nieswiadomy, R. (1993). Foundations of nursing research. Connecticut: Appleton & Lange.
- Nolan, M., & Mock, V. (2004). A conceptual framework for end-of-life care: A reconsideration of factors influencing the integrity of the human person. Journal of Professional Nursing, 20(6), 351-360.
- Norlander, L., & McSteen, K. (2000). The kitchen table discussion: A Creative way to discuss end-of-life issues. Home Healthcare Nurse, 18(8), 532-539.
- NSW Health. (2004). Guidelines for end of life care and decision-making. Sydney: NSW Health.
- NSW Health. (2004). Using advance care directives. Sydney: NSW Health.
- O'Brien, L. A., Grisso, J. A., Maislin, G., LaPenn, K., Krotki, K. P., Greco, P. J., Siegert, E. A., & Evans, L. K. (1995). Nursing home residents' preferences for life-sustaining treatments. Journal of the American Medical Association, 274(22), 1775-1779.
- O'Donnell, H., Phillips, R. S., Wenger, N., Teno, J., Davis, R. B., & Hamel, M. B. (2003). Preferences for cardiopulmonary resuscitation among patients 80 years or older: The views of patients and their physicians. Journal of the American Medical Directors Association, 4(3), 139-144.
- Onwuteaka-Philipsen, B. D., Fisher, S., Cartwright, C., Deliens, L., Miccinesi, G., Norup, M., Nilstun, T., van der Heide, A., van der Wal, G., & EURELD Consortium. (2006). End-of-life decision making in Europe and Australia. Archives of Internal Medicine, 166(8), 921-929.
- Ott, B. (1999). Advance directive: The emerging body of research. American Journal of Critical Care, 8(1), 514-519.

- Palker, N. B., & Nettles-Carlson, B. (1995). The prevalence of advance directives: lessons from a nursing home. Nurse Practitioner, 20(2), 7-8, 13, 17-18.
- Parkman, C. A., & Calfee, B. E. (1997). Advance directives. Nursing, 27(4), 48-53.
- Patterson, B. J. (1995). The process of social support: Adjusting to life in a nursing home. Journal of Advance Nursing, 21(4), 682-689.
- Patton, M. (1990). Qualitative evaluation and research methods. London: SAGE Publications.
- Pearlman, R. A., Cole, W. G., Patrick, D. L., Starks, H. E., & Cain, K. C. (1995). Advance care planning: Eliciting patient preferences for life-sustaining treatment. Patient Education & Counselling, 26(1-3), 353-361.
- Perrin, K. O. (1997). Giving voice to the wishes of elders for end-of-life care. Journal of Gerontological Nursing, 23(3), 18-27, 50-56.
- Phillips, R. S., Wenger, N. S., Teno, J., Oye, R. K., Youngner, S., Califf, R., Layde, P., Desbiens, N., Connors, A. F Jr., & Lynn, J. (1996). Choices of seriously ill patients about cardiopulmonary resuscitation: Correlates and outcomes. American Journal of Medicine, 100(2), 128-137.
- Polit, D. E., & Hungler, B. P. (1991). Nursing research, principles and methods. Philadelphia: Lippincott.
- Polit, D. F., & Hungler, B. P. (1993). Essentials of nursing research. Philadelphia: Lippincott.
- Polit, D. F., & Hungler, B. P. (1995). Nursing research: Principles and methods. Philadelphia: Lippincott.
- Pollard, B. J. (1991). Withdrawing life-sustaining treatment from severely brain-damaged persons. The Medical Journal of Australia, 154, 559-561.
- Puopolo, A. L., Kennard, M. J., Mallatratt, L., Follen, M. A., Desbiens, N. A., Connors, A. F. Jr., Califf, R., Walzer, J., Soukup, J., Davis, R. B., & Phillips, R. S. (1997). Preferences for cardiopulmonary resuscitation. Image: Journal of Nursing Scholarship, 29(3), 229-235.
- Ratner, E. R., Norlander, L., McSteen, K. L., Young, J. E., Odegard, L., & Myers, R. N. (1999). Improving end-of-life care within an integrated health system. The Medical Journal of Allina, 8, 27-30.
- Reed, P. G. (1991a). Self-transcendence and mental health of oldest-old adults. Nursing Research, 40(1), 5-11.
- Reed, P. G. (1991b). Toward a nursing theory of self-transcendence deductive reformation using developmental theories. Advances in Nursing Science, 13(4), 64-77.
- Resnick, B., & Andrews, C. (2002). End-of-life treatment preferences among older adults:

- A nurse practitioner initiated intervention. Journal of The American Academy of Nurse Practitioners, 14(11), 517-522.
- Robinson, M. K., DeHaven, M. J., & Koch, K. A. (1993). Effects of the Patient Self-Determination Act on patient knowledge and behavior. The Journal of Family Practice, 37(4), 363-368.
- Rosenfeld, K. F., Wenger, N. S., & Kagawa-Singer, M. (2000). End of life decision-making: A qualitative study of elderly individuals. Journal of General and Internal Medicine, 15, 620-625.
- Ryan, C. J. (1996). Betting your life: An argument against certain advance directives. Journal of Medical Ethics, 22(2), 95-99.
- Sanderson, C. D. (1995). Educating the community on advance directives. Tennessee Nurse, 58(2), 23.
- Sansone, P., & Phillips, M. (1995). Advance directives for elderly people: Worthwhile cause or wasted effort? Social Work, 40(3), 397-401.
- Sayers, G. M., Schofield, I., & Aziz, M. (1997). An analysis of CPR decision-making by elderly patients. Journal of Medical Ethics, 23(4), 207-212.
- Sayers, G. M., Barratt, D., Gothard, C., Onnie, C., Perera, S., & Schulman, D. (2001). The value of taking an 'ethics history'. Journal of Medical Ethics, 27(2), 114-117.
- Schatzman, L., & Strauss, A. (1973). Field research: Strategies for a natural sociology. New Jersey: Prentice Hall.
- Scherer, Y., Jezewski, M. A., Graves, B., Wu, Y-W. B., & Bu, X. (2006). Advance directives and end-of-life decision making: Survey of critical care nurses' knowledge, attitudes, and experience. Critical Care Nurse, 26(4), 30-41.
- Schiff, R., Rajkumar, C., & Bulpitt, C. (2000). Views of elderly people on living wills: Interview study. BMJ, 320(7250), 1640-1641.
- Schiff, R., Sacare, P., Snook, J., Rajkumar, C., & Bulpitt, C. (2006). Living will and the Mental Capacity Act: A postal questionnaire survey of UK geriatricians. Age and Ageing, 35(2), 116-121.
- Schmidt, T. A., Hickman, S. E., Tolle, S. W., & Brooks, H. S. (2004). The physician orders for life-sustaining treatment program: Oregon emergency medical technicians' practical experiences and attitudes. Journal of the American Geriatrics Society, 52(9), 1430-1434.
- Schneider, Z., Elliot, D., Beanland, C., LoBiondo-Wood, G., & Haber, J. (2003). Nursing research: Methods, critical appraisal and utilisation. Sydney: Mosby.
- Schneiderman, L. J., Kronick, R., Kaplan, R. M., Anderson, J. P., & Langer, R. D. (1992). Effects of offering advance directives on medical treatments and costs. Annals of Internal Medicine, 117(7), 599-606.

- Seal, M. (2007). Patient advocacy and advance care planning. Australian Journal of Advanced Nursing, 24(4), 29-35.
- Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S. H., & Clark, D. (2004). Planning for the end of life: The views of older people about advance care statements. Social Science and Medicine, 59(1), 57-68.
- Shanley, C., & Wall, S. (2004). Promoting patient autonomy and communication through advance care planning: A challenge for nurses in Australia. Australian Journal of Advanced Nursing, 21(3), 32-38.
- Shapiro, J., & Bowles, K. (2002). Nurses' and consumers' understanding of and comfort with the patient self-determination Act. Journal of Nursing Administration, 32(10), 503-508.
- Silverman, H. J., Fry, S. T., & Armistead, N. (1994). Nurses' perspectives on implementation of the patient self-determination act. The Journal of Clinical Ethics, 5, 30-37.
- Skene, L. (2005). The Schiavo and Korp cases: Conceptualising end-of-life decision-making. Journal of Law and Medicine, 223, 223-229.
- Skilbeck, J. K., & Payne, S. (2005). End of life care: A discursive analysis of specialist palliative care nursing. Journal of Advance Nursing, 51(4), 325-334.
- Smith, A. K., Ries, A. P., Zhang, B., Tulskey, J. A., Prigerson, H. G., & Block, S. D. (2006). Resident approaches to advance care planning on the day of hospital admission. Archives of Internal Medicine, 166(15), 1597-1602.
- Solomon, M., Jennings, B., Dickey, N., Pittman, M., Orentlicher, D., & Lombard, J. (1996). The SUPPORT project and improving care for seriously ill patients. Journal of American Medical Association, 275(16), 1229-1230.
- Solomon, M. Z., O'Donnell, L. J., Jennings, B., Guilfoyle, V., Wolf, S. M., Nolan, K., Jackson, R., Koch-Wester, D., & Donnelly, S. (1993). Decisions near the end of life: Professional views on life-sustaining treatments. American Journal of Public Health, 83(1), 14-23.
- Soskis, C. W. (1997). End-of-life decisions in the home care setting. Social Work in Health Care, 25(1/2), 107-116.
- Spradley, J. P. (1980). Participant observation. London: Holt, Rinehart and Winston.
- Stake, R. E. (1994). Case studies. In N. K. Denzin, & Y. S. Lincoln (Eds.). Handbook of qualitative research (pp. 236-247). London: SAGE Publications.
- Stake, R. E. (2005). Qualitative case studies. In N. K. Denzin, & Y. S. Lincoln (Eds.). The Sage handbook of qualitative research (pp. 443-466). London: SAGE Publications.
- Steinberg, M. A., Cartwright, C. M., MacDonald, S. M., & Najman, J. M. (1997). Self-

- determination in terminal care: A comparison of GP and community members' responses. Australian Family Physician, 27, 703-707.
- Steinberg, M., Najman, J. M., Cartwright, C. M., MacDonald, S. M., & Williams, G. M. (1997). End-of-life decision-making: Community and medical practitioners' perspectives. Medical Journal of Australia, 166(3), 131-134.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, M., & Tulsky, L. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. Journal of the American Medical Association, 284, 2476-2482.
- Sterling, Y. M., & McNally, J. A. (1992). Single subject research for nursing practice. Clinical Nurse Specialist, 6(1), 21-26.
- Stewart, C. (1996). Who decides when I can die?: Problems concerning proxy decisions to forego medical treatment. Journal of Law and Medicine, 4, 386.
- Stewart, C. (2005). The Australian experience of advance directives and possible future directions. Australasian Journal on Ageing, 24(Supplement), S25-S29.
- Stewart, K., & Bowker, L. (1998). Advance directives and living wills. Postgraduate Medical Journal, 74(869), 151-156.
- Stolman, C. J., Gregory, O. J., Dunn, D., & Levine, J. L. (1990). Evaluation of patient, physician, nurses and family attitudes towards do not resuscitate orders. Archives of Internal Medicine, 150, 653-658.
- Strauss, A. (1987). Qualitative analysis for social scientists. New York: Cambridge University Press.
- Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park: SAGE.
- Streubert, H., & Carpenter, D. (1999). Qualitative research in nursing: Advancing the humanistic imperative. New York, Lippincot.
- Sulmasy, D. P., Terry, P. B., Weisman, C. S., Miller, D. J., Stallings, R. Y., Vettese, M. A., & Haller, K. B. (1998). The accuracy of substituted judgments in patients with terminal diagnoses. Annals of Internal Medicine, 128(8), 621-629.
- Support Study Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalised patients: The study to understand prognoses and preferences for outcomes and risks of treatment (SUPPORT). Journal of the American Medical Association, 274 (20), 1591-1598.
- Talbot, L. A. (1995). Principles and practice of nursing research. Sydney: Mosby.
- Taylor, S., & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meaning. New York: A Wiley-Interscience Publication.



- Taylor, C. (1995). Medical futility and nursing. Image: Journal of Nursing scholarship, 27(4);,301-306.
- Taylor, D., & Cameron, P. (2002). Advance care planning in Australia: Overdue for improvement. Internal Medicine Journal, 32(9/10), 475-480.
- Tennstedt, S. L. (2002). Commentary on "Research design in end-of-life research: State of Science". The Gerontologist, 42(Special Issue), 99-103.
- Teno, J. M., & Hill, T. P. (1994). Advance care planning: Priorities for ethical and empirical research. Hastings Center Report, 24(6), S32-S36.
- Teno, J. M., Hakim, R. B., Knaus, W. A., Wenger, N. S., Phillips, R. S., Wu, A.W., Layde, P., Connors, A. F Jr., Dawson, N. V., & Lynn, J. (1995). Preferences for cardiopulmonary resuscitation: Physician-patient agreement and hospital resource use. Journal of General Internal Medicine, 10(4), 179-186.
- Teno, J., Branco, K., Mor, V., Phillips, C., Hawes, C., Morris, J., & Fries, B. (1997). Changes in advance care planning in nursing homes before and after the Patient Self-Determination Act: Report of a 10 State survey. Journal of American Geriatrics Society, 45(8), 939-944.
- Teno, J. M., Lynn, J., Phillips, R. S., Murphy, D., Youngner, S. J., Bellamy, P., Connors, A. F. Jr., Desbiens, N. A., Fulkerson, W., & Knaus, W. A. (1994). Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Journal of Clinical Ethics, 5(1), 23-30.
- Teno, J. M., Lynn, J., Wegner, N., Phillips, R. S., Russell, S., Murphy, D., Connors, A. F Jr., Desbiens, N., Fulkerson, W., Bellamy, P., & Knaus, W. A. (1997). Advance directives for seriously-ill hospitalised patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention. Journal of American Geriatric Society, 45(4), 500-507.
- The Benevolent Society. (2005, September). Advance care directives policy. Sydney: The Benevolent Society.
- Thompson, T. D., Barbour, R. S., & Schwartz, L. (2003). Health professionals' view on advance directives: A qualitative interdisciplinary study. Palliative Medicine, 17(5), 403-409.
- Tonelli, M. R. (1996). Pulling the plug on living wills: A critical analysis of advance directives. Chest, 110(3), 816-822.
- Tornstam, L. (1994). Gerotranscendence - a theoretical and empirical exploration. In L. E. Thomas., & S. A. Eisenhandler (Eds.). Aging and religious dimension (pp. 203-225). Westport: Greenwood Publishing Group.
- Tornstam, L. (1997). Gerotranscendence: The contemplative dimension of ageing. Journal of Aging Studies, 11(2), 143-154.

- Tornstam, L. (1999/2000). Transcendence in later life. Generations, 23(4), 10-14.
- Travis, S., Mason, J., Mallett, J., & Laberty, D. (2001). Guidelines in respect of advance directives: The position in England. International Journal of Palliative Nursing, 7, 493-500.
- Tulsky, J. A., Fischer, G. S., Rose, M. R., & Arnold, R. M. (1998). Opening the Black Box: How Do Physicians Communicate about Advance Directives? Annals of Internal Medicine, 129(6), 441-449.
- Tuttas, C. (2002). The facts of end-of-life care. Journal of Nursing Care Quarterly, 16(2), 10-16.
- United Hawaiian (UH) Center on Aging (2002). The complete life: Care of the dying. Advance directives: Clarification. Resources for the Aging Network. Retrieved February 13, 2005 from [www.health.nsw.gov.au/health\\_pr/chronic\\_care/ccr/resources/acd07.xls](http://www.health.nsw.gov.au/health_pr/chronic_care/ccr/resources/acd07.xls)
- Virmani, J., Schneiderman, L. J., & Kaplan, R. M. (1994). Relationship of advance directives to physician-patient communication. Archives of Internal Medicine, 154(8), 909-913.
- Volandes, A. E., Lehmann, L. S., Cook, F., Shaykevich, S., Abbo, E. D., & Gillick, M. R. (2007). Using video images of dementia in advance care planning. Archives of Internal Medicine, 167, 828-833.
- Von Bertalanffy, L. (1968). General system theory: Foundations, development, and applications. New York: George Braziller.
- Von Bertalanffy, L. (1975). Perspectives on general system theory. New York: George Braziller.
- Waddell, C., Clarnette, R., Smith, M., & Oldham, L. (1997). Advance directives affecting medical treatment choices. Journal of Palliative Care, 13(2), 5-8.
- Waddell, C., Clarnette, R., Smith, M., Oldham, L., & Kellehear, A. (1996). Treatment decision-making at the end of life: A survey of Australian doctors' attitudes towards patients' wishes and euthanasia. Medical Journal of Australia, 165(10), 540-544.
- Wade, M. (2004). Growing fears over booming aged numbers. Sydney Morning Herald: Sydney.
- Wadensten, B., & Carlsson, M. (2001). A qualitative study of nursing staff members' interpretations of signs of gerotranscendence. Journal of Advance Nursing, 36(5), 635-642.
- Wadensten, B., & Carlsson, M. (2003). Theory-driven guidelines for practical care of older people, based on the theory of gerotranscendence. Journal of Advance Nursing, 41(5), 462-470.

- Wadensten, B. (2005). Introducing older people to the theory of gerotranscendence. Journal of Advance Nursing, 52(4), 381-388.
- Wallace, N., Pollard, R., & Needham, K. (2004). Hospital removes life support after court bid fails. Sydney Morning Herald: Sydney.
- Weeks, W. B., Kofoed, L. L., Wallace, A. E., & Welch, H. G. (1994). Advance directives and the cost of terminal hospitalisation. Archives of Internal Medicine, 154, 2077-2083.
- Weiler, K., Eland, J., & Buckwalter, K. C. (1996). Iowa nurses' knowledge of living wills and perceptions of patient autonomy. Journal of Professional Nursing, 12, 245-252.
- Westley, C., & Briggs, L. A. (2004). Using the stages of change model to improve communication about advance care planning. Nursing Forum, 39(3), 5-12.
- White, P. D. (1997). The role of the critical care nurse in counselling families about advance directives. Critical Care Nursing Clinics of North America, 9, 53-61.
- Wiseman, J., & Aron, M. (1970). Field projects for sociology students. Cambridge: Schenkman Publishing Company, INC.
- Wowchuk, S. M., McClemenet, S., & Bond Jr. J. (2006). The challenge of providing palliative care in the nursing home: Part 1 external factors. International Journal of Palliative Nursing, 12(6), 260-267.
- Wurzbach, M. F. (2002). End-of-life treatment decisions in long-term care. Journal of Gerontological Nursing, 28(6), 14-21.
- Yin, R. K. (1989). Case study research: Design and methods. Newbury Park: SAGE Publications.
- Yin, R. K. (1993). Applications of case study research. London: SAGE Publications.
- Yin, R. K. (1994). Case study research: Design and methods. London: SAGE Publications.
- Yin, R. K. (2003a). Applications of case study research. London: SAGE Publications.
- Yin, R. K. (2003b). Case study research: Design and methods. London: SAGE Publications.
- Yuen, F. (1991). Case study of learning milieu: The modifying effect of the workplace. Journal of Advance Nursing, 16(11), 1290-1295.
- Zweibel, N. R., & Cassel, C. K. (1989). Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. Gerontologist, 29(5), 615-621.

## Appendices

- Appendix 1. Data collection: Timeframe and processes
- Appendix 2. Information letter for the DONs
- Appendix 3. Permission to enter the premise of
- Appendix 4. Announcement to non-participant residents and families in the facility
- Appendix 5. Announcement to al non-participant staff in the facility
- Appendix 6. Information letter for the expert CNC
- Appendix 7. Consent form for the expert CNC
- Appendix 8. Preliminary work
- Appendix 9. Information letter for residents and families
- Appendix 10. Consent form for observation and interview
- Appendix 11. Reminder letter for the consent form
- Appendix 12. Information letter for RNs
- Appendix 13. Interview schedule for residents and family members
- Appendix 14. Interview schedule for the RNs
- Appendix 15. Consent form for the transcriptionist
- Appendix 16. Audit trail Part A
- Appendix 17. Audit trail Part B
- Appendix 18. Framework of questions to explore the experience of residents, family members, and RNs with ACP
- Appendix 19. The exemplar and the roles and functions of nurses in ACP

## Appendix 1. Data collection: Timeframe and processes

Step	Mission	Timeframe (total 24-26 weeks)													
		2	4	6	8	10	12	14	16	18	20	22	24	26	
Step 1: Entering the field	• Undertake Part 1 participant observation and write up field notes														
	• Visit each RACF & introduce myself to the manager, staff, residents, and families														
	• Present the research project to potential participants by mutual agreement														
	• Distribute information letters & consent forms by the DONs														
Step 2: collecting data in the field	• Collect consent forms for Part 2 observations and interviews														
	• Distribute a reminder letter by the DONs														
	• Undertake Part 2 participant observation & write up field notes in each RACF														
	• Undertake document reviews within each RACF														
	• Arrange interview schedule with consenting participants														
	• Commence interviews with consenting participants at a suitable place within the RACFs														
	• Complete interviews with consenting participants														
Step 3: departing the field	• Prepare to exit the field and establish closure in relationships with people in the field														
	• Follow up the participants if necessary														
	• Provide report on fieldwork for each facility														

## Appendix 2. Information letter for the Directors of Nursing (DONs)

### Researcher

Sarah (Yeun-Sim) Jeong. RN., BN., MN., PhD Candidate.  
School of Nursing & Midwifery.  
University of Newcastle.  
Email: [Sarah.Jeong@newcastle.edu.au](mailto:Sarah.Jeong@newcastle.edu.au)  
Tel: (02) 4320-3941  
Fax: (02) 4320-2620

### Supervisors

Professor Margaret McMillan.  
Email: [Margaret.McMillan@newcastle.edu.au](mailto:Margaret.McMillan@newcastle.edu.au)  
Tel: (02) 4921-6005  
Fax: (02) 4921- 2020

Dr Isabel Higgins  
Email: [Isabel.Higgins@newcastle.edu.au](mailto:Isabel.Higgins@newcastle.edu.au)  
Tel: (02) 4921-6347  
Fax: (02) 4921-6301

<p align="center"><b>Information Statement for the Research Project: Directors of Nursing</b></p> <p align="center"><b>Advance Care Planning (ACP) and Advance Care Directives (ACDs) in Residential Aged Care Facilities (RACFs) in Australia: A case study.</b></p>
---

Researchers:	
Professor Margaret McMillan (Chief Investigator) Faculty of Health The University of Newcastle	
Sarah Jeong (PhD Student) School of Nursing and Midwifery The University of Newcastle	Dr Isabel Higgins (Co-Supervisor) School of Nursing and Midwifery The University of Newcastle

You are invited to take part in the research project identified above which is being conducted by Sarah Jeong from the School of Nursing and Midwifery at The University of Newcastle. Sarah Jeong who does not work in this nursing home, is conducting the research as part of her PhD under the supervision of Professor Margaret McMillan, and Dr Isabel Higgins.

### ***Why is the research being done?***

- The purpose of this research is to explore the experiences of residents, their family members, and nurses with Advance Care Planning (ACP) and Advance Care Directives (ACDs). ACP and ACDs are part of what is known as palliative care, which usually includes assessment of, and conversations about a person's understanding of their medical history and condition, their personal values and preferences and the wishes of those close to them with regard to the kind of care they would like to receive.
- Information gained from this study will inform residents, families and nurses of the nature and scope of choices available to residents about their care as

they approach the stage of decision-making around their care, which may or may not include “end-of-life” decisions.

- There is very little written about the topic of Advance Care Planning and Advance Care Directives and the views and experiences of residents, their family members, and nurses who provide care have not been adequately explored.

***Who can participate in the research?***

- I am seeking to involve residents, their families and Registered Nurses as participants in the research project.

***What choice do you have?***

- Participation in this research is entirely your choice.
- Only those residential aged care facilities that give their permission to enter their premises will be included in this project.
- Only those residents and family members who give their informed consent will be included in this project.
- Whether or not you decide to participate, your decision will not disadvantage you in any way.
- If you do decide to participate, you have the right to withdraw from the project at any time without giving a reason.

***What will the researcher be doing in your nursing home?***

- I will ask you to please represent residents’, family members’, and RNs’ wishes to have or not to have the student researcher present in your Residential Aged Care Facility.
- I will be observing the whole context of your Nursing Home over a three-month period with regard to the nursing management of end-of-life care.
- I will be making notes to ensure that I have an accurate record.
- The focus of my observation will be on the way the residents-family members-doctors-nursing staff inform, integrate and sustain Advance Care Planning into the care of residents.
- I will also be observing how nursing staff respond to Advanced Care Planning and Advance Care Directives.
- I will be interviewing only those residents, family members, and Registered Nurses who give their consent.
- Interviews will be conducted in private, at a date, time and place of mutual convenience.

***What are the risks and benefits of participating?***

- I cannot promise you any personal benefit from participating in this research other than an opportunity to have greater insight into aspects of end-of-life care. Insight gained in this study may be used to promote better plans of treatment for residents and families in the future.
- There are no risks that affect you personally and/or your organisation in any way.

***How will your privacy be protected?***

- All information provided will remain confidential.
- Within written records, all names, including those of residential aged care facilities, will be altered.

- Individual participants will not be identified in any reports arising from the project.
- An experienced person well versed in the ethics of research will undertake the transcription of the audiotape. S/he will be required to sign a Promise of Confidentiality Agreement prior to the transcription.
- During the study computer records will be given a password and all names and contact details will be kept separate from records.
- While the study is underway, data will be kept on my home computer and backed up on a USB drive that will remain in my possession and be password protected.
- All paper records and tapes will be kept in a locked cabinet in my home.
- Only the researchers will have access to this data.
- At the completion of the interviews all participants' contact details will be destroyed.
- At the completion of the study all computer files will be stored with the paper records and tapes in a locked cabinet the School of Nursing and Midwifery for a period of five years.
- At the end of the five-year period, data on the USB drive will be erased, the tapes destroyed and paper-based records shredded.

***How will the information collected be used?***

- Results from this study may be published both in my PhD dissertation and in scientific journals.
- Individual participants will not be identified in any reports arising from the research project.
- The findings will be available within two years and will be sent to you upon request. Please contact the researchers by e-mail, phone or mail to request the summary of findings.

***What do you need to do to participate?***

- If there is anything you do not understand, or if you would like to obtain further information about the project, you can contact one of the researchers.
- If you are willing to participate in the research project, please sign the attached permission form and return the form via fax.
- Read this Information Statement and be sure you understand its contents before you sign the permission form.
- You are reminded that you can change your mind at any time if you do change your mind.

Thank you for considering this invitation.

Professor Margaret McMillan (Chief Investigator)  
Faculty of Health  
The University of Newcastle

Sarah Jeong (PhD Student)  
School of Nursing and Midwifery  
The University of Newcastle

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-104-0905. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02 492 16333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).*



### Appendix 3. Permission to enter the premise of

---

(Name of your facility)

I, ..... (full name) have received information from Sarah (Yeun-Sim) Jeong about her study “Advance Care Planning Program in Residential Aged Care Facilities”. I have retained a copy of this information and I am satisfied that I understand the purposes and processes Sarah Jeong is using. I understand that privacy will be protected and confidentiality maintained. I also realise that I can revoke the permission and withdraw from the study at any time without any explanation.

I give Sarah Jeong my permission to enter the premise of this residential aged care facility.

Print name ..... Position: .....

Signature.....

Date.....

Contact details:

Tel: (W) .....

(M) .....

Email.....

#### Appendix 4. Announcement to non-participant residents and families in the facility

##### **Researcher**

Sarah (Yeun-Sim) Jeong. RN., BN., MN., PhD Candidate.  
School of Nursing & Midwifery.  
University of Newcastle.  
Email: [Sarah.Jeong@newcastle.edu.au](mailto:Sarah.Jeong@newcastle.edu.au)  
Tel: (02) 4320-3941  
Fax: (02) 4320-2620

##### **Supervisors**

Professor Margaret McMillan.  
Email: [Margaret.McMillan@newcastle.edu.au](mailto:Margaret.McMillan@newcastle.edu.au)  
Tel: (02) 4921-6005  
Fax: (02) 4921- 2020

Dr Isabel Higgins  
Email: [Isabel.Higgins@newcastle.edu.au](mailto:Isabel.Higgins@newcastle.edu.au)  
Tel: (02) 4921-6347  
Fax: (02) 4921-6301

#### **Observation & Interview Information Statement for the Research Project**

#### **Advance Care Planning (ACP) and Advance Care Directives (ACDs) in Residential Aged Care Facilities (RACFs) in Australia: A case study.**

<b>Researchers:</b>	
Professor Margaret McMillan (Chief Investigator) Faculty of Health The University of Newcastle	
Sarah Jeong (PhD Student) School of Nursing and Midwifery The University of Newcastle	Dr Isabel Higgins (Co-Supervisor) School of Nursing and Midwifery The University of Newcastle

#### **Dear Residents and family members,**

Sarah Jeong, who does not work in this nursing home, is conducting the research as part of her PhD under the supervision of Professor Margaret McMillan, and Dr Isabel Higgins.

#### ***Why is the research being done?***

- The purpose of the project is to investigate the impact on and experiences of residents and families with the Advance Care Planning and Advance Care Directives (ACDs).
- This study will provide us with information that may be used to promote best care for residents and families in the future.

***How does this research concern you?***

Not all residents and family members will be involved in the research project. There is no disadvantage or harm to people who do not participate in the research project. If you are not participating in the research project, your routine life-style in this nursing home will be maintained as usual. Should you have any concern with the presence of the researcher in your personal space, please do not hesitate to express your wishes.

You will also notice the following sign placed within the nursing home.

*Over the period between February, 2006 and July, 2006 this nursing home is being observed by the researcher Sarah Jeong. If you do not wish to be observed during your visit, please feel free to ask the researcher or any other nursing staff to terminate observation or to have another area for the visit. If the researcher does not hear from you or staff, consent to participate will be assumed. If you need more information, please contact senior nursing staff or the researcher.*

Thank you very much.

Yours faithfully,

Sarah (Yeun-Sim) Jeong

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-104-0905. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02 492 16333), email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).*

## Appendix 5. Announcement to non-participant staff in the facility

### Researcher

Sarah (Yeun-Sim) Jeong. RN., BN., MN., PhD Candidate.  
School of Nursing & Midwifery.  
University of Newcastle.  
Email: [Sarah.Jeong@newcastle.edu.au](mailto:Sarah.Jeong@newcastle.edu.au)  
Tel: (02) 4320-3941  
Fax: (02) 4320-2620

### Supervisors

Professor Margaret McMillan.  
Email: [Margaret.McMillan@newcastle.edu.au](mailto:Margaret.McMillan@newcastle.edu.au)  
Tel: (02) 4921-6005  
Fax: (02) 4921- 2020

Dr Isabel Higgins  
Email: [Isabel.Higgins@newcastle.edu.au](mailto:Isabel.Higgins@newcastle.edu.au)  
Tel: (02) 4921-6347  
Fax: (02) 4921-6301

### **Observation & Interview Information Statement for the Research Project**

**Advance Care Planning (ACP) and Advance Care Directives (ACDs) in Residential  
Aged Care Facilities (RACFs) in Australia: A case study.**

<b>Researchers:</b>	
Professor Margaret McMillan (Chief Investigator) Faculty of Health The University of Newcastle	
Sarah Jeong (PhD Student) School of Nursing and Midwifery The University of Newcastle	Dr Isabel Higgins (Co-Supervisor) School of Nursing and Midwifery The University of Newcastle

**Dear staff,**

Sarah Jeong, who does not work in this nursing home, is conducting the research as part of her PhD under the supervision of Professor Margaret McMillan, and Dr Isabel Higgins.

### ***Why is the research being done?***

- The purpose of the project is to investigate the impact on and experiences of residents and families with the Advance Care Planning and Advance Care Directives (ACDs).
- This study will provide us with information that may be used to promote best care for residents and families in the future.
- This study will also increase the body of knowledge in the scope of opportunities for nurses in the ACP process and ACDs, and the extent of nursing participation.

***How does this research concern you?***

Not all nursing staff will be involved in the research project. There is no disadvantage or harm to people who do not participate in the research project. Should you have any concern with the presence of the researcher in your personal space, please do not hesitate to express your wishes.

You will also notice the following sign in the nurses' station and staff common room.

*During the period between February, 2006 and July, 2006 this nursing home is being observed by the researcher Sarah Jeong. If you do not wish to be observed or have a conversation with the researcher about what you are doing, please feel free to tell the researcher that you would like to be excluded from the observation. If the researcher does not hear from you, consent to participate will be assumed.*

Thank you very much.

Yours faithfully,

Sarah (Yeun-Sim) Jeong

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-104-0905. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02 492 16333), email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).*

## Appendix 6. Information letter for the CNC

### Researcher

Sarah (Yeun-Sim) Jeong. RN., BN., MN., PhD Candidate.  
School of Nursing & Midwifery.  
University of Newcastle.  
Email: [Sarah.Jeong@newcastle.edu.au](mailto:Sarah.Jeong@newcastle.edu.au)  
Tel: (02) 4320-3941  
Fax: (02) 4320-2620

### Supervisors

Professor Margaret McMillan.  
Email: [Margaret.McMillan@newcastle.edu.au](mailto:Margaret.McMillan@newcastle.edu.au)  
Tel: (02) 4921-6005  
Fax: (02) 4921- 2020

Dr Isabel Higgins  
Email: [Isabel.Higgins@newcastle.edu.au](mailto:Isabel.Higgins@newcastle.edu.au)  
Tel: (02) 4921-6347  
Fax: (02) 4921-6301

### **Observation & Interview Information Statement for the Research Project: Clinical Nurse Consultant**

### **Advance Care Planning (ACP) and Advance Care Directives (ACDs) in Residential Aged Care facilities (RACFs) in Australia: A case study.**

<b>Researchers:</b>	
Professor Margaret McMillan (Chief Investigator) Faculty of Health The University of Newcastle	
Sarah Jeong (PhD Student) School of Nursing and Midwifery The University of Newcastle	Dr Isabel Higgins (Co-Supervisor) School of Nursing and Midwifery The University of Newcastle

You are invited to take part in the research project identified above which is being conducted by Sarah Jeong from the School of Nursing and Midwifery at The University of Newcastle. Sarah Jeong is conducting the research as part of her PhD under the supervision of Professor Margaret McMillan and Dr Isabel Higgins.

### ***Why is the research being done?***

- The purpose of this research is to explore the experiences of residents, their family and nurses with Advance Care Planning (ACP) and Advance Care Directives (ACDs). ACP and ACDs are part of what is known as palliative care which usually includes assessment of, and conversations about a person's understanding of her/his medical history and condition, her/his personal values and preferences and the wishes of those close to her/him with regard to the kind of care s/he would like to receive.

- Information gained from this study will inform residents, families and nurses of the nature and scope of choices available to residents about their care as they approach the stage of decision-making around their care which may or may not include “end-of-life” decisions.
- There is very little written about the topic of Advance Care Planning and Advance Care Directives and the views and experiences of residents, their family and nurses who provide care have not been adequately explored.

***Who can participate in the research?***

- I am seeking to involve an expert Clinical Nurse Consultant, residents, their families and nurses as participants in the research project.

***What choice do you have?***

- Participation in this research is entirely your choice.
- Within the Area Health Service and the Residential Aged Care Facilities, only those residents, family members and nurses who give their informed consent will be included in this project.
- Whether or not you decide to participate, your decision will not disadvantage you in any way.
- If you do decide to participate, you may withdraw from the project at any time without giving a reason and without affecting your relationship with your employer or the University.
- You may also withdraw all or any data you have provided to the researcher.

***What you will be asked to do?***

Your involvement will include one or both of the following:

- i) **Being part of a period of observation undertaken by me of you and your work environment in the Area Health Service and Nursing Homes over a three-month period.**
  - I will ask you to please represent residents’, family members’, and RNs’ wishes to have or not to have the student researcher present in your visits in the Residential Aged Care Facilities.
  - I will be observing the whole context of your work environment with regard to the nursing management of end-of-life care.
  - The focus of my observation will be on the way the resident-family members-doctors-nursing staff inform, integrate and sustain Advance Care Plans into their care.
  - I will also be observing how nursing staff respond to Advance Care Planning and Advance Care Directives.
  - I will be making notes to ensure that I have an accurate record.
- ii) **Participation in an interview**
  - If you decide to participate you will be asked to participate in one audio-taped interview conducted by Sarah Jeong.
  - The interview will take up to one hour and with your permission will be tape-recorded.
  - During the interview you can turn the tape off at any time.
  - During the interview I will ask you to share your experience of decision-making about the nature and extent of your care.
  - The tapes will be transcribed and the data used for analysis.
  - You will be able to review the recording and/or transcriptions to edit or erase your contribution if required.

- Interviews will be conducted in private, at a date, time and place of mutual convenience.

***What are the risk and benefits of participating?***

- I cannot promise you any personal benefit from participating in this research.
- However, it is expected that the study will increase the body of knowledge regarding scope of opportunities for nurses to support residents and their families in the Advance Care Planning process and the use of Advance Care Directives, and will shed light on the nature and extent of nursing participation in those processes.
- The study may promote the valuable role that an expert nurse plays in assisting residents to achieve their choices in end-of-life care decision-making.
- The potential risk centres on the uniqueness of your role and the likelihood of identification through any published material.

***How will your privacy be protected?***

- All information that you provide will remain confidential.
- Within written records all names, including those of health-care facilities, will be altered and you will be asked to choose a pseudonym to replace your real name.
- Privacy and confidentiality will be maintained as far as possible within the constraints of the unique nature of your role.
- Individual participants will not be identified in any reports arising from the project.
- An experienced person well-versed in the ethics of research will undertake the transcription of the audiotape. S/he will be required to sign a Promise of Confidentiality Agreement prior to the transcription.
- During the study computer records will be given a password and all names and contact details will be kept separate from records.
- While the study is underway data will be kept on my home computer and backed up on a USB drive that will remain in my possession and be password-protected.
- All paper records and tapes will be kept in a locked cabinet in my home.
- Only the researchers will have access to this data.
- At the completion of the interviews all participants' contact details will be destroyed.
- At the completion of the study all computer files will be stored with the paper records and tapes in a locked cabinet the School of Nursing and Midwifery for a period of five years.
- At the end of the five-year period, data on the USB drive will be erased, the tapes destroyed and paper-based records shredded.

***How will the information collected be used?***

- Results from this study may be published both in my PhD dissertation and in scientific journals.
- Individual participants will not be identified in any reports arising from the research project.
- You are welcome to a copy of the transcript of your interview which will be available within two months, and/or a copy of the summary of the findings of the study. The findings will be available within two years and will be sent to you upon request. Please contact the researchers by e-mail, phone or mail to request the summary of findings.



- I am happy to negotiate co-authorship of any conference papers or journal articles published throughout the research process.

***What do you need to do to participate?***

- If there is anything you do not understand, or if you would like to obtain further information about the project, you can contact one of the researchers.
- If you are willing to participate in the research project, please sign the attached consent form and return the consent form to Sarah Jeong either by post mail or fax.
- Please be advised that only one interview session will be conducted.
- Read this Information Statement and be sure you understand its contents before you sign the consent form and return it to Sarah Jeong.
- You are reminded that you can change your mind at any time and are not obliged to take part in the research project if you do change your mind.

Thank you for considering this invitation.

Professor Margaret McMillan (Chief Investigator)  
Faculty of Health  
The University of Newcastle

Sarah Jeong (PhD Student)  
School of Nursing and Midwifery  
The University of Newcastle

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-104-0905. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02 492 16333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).*

## Appendix 7. Consent form for the CNC

I, ..... have received information from Sarah (Yeun-Sim) Jeong about her study “Advance Care Planning program in Residential Aged Care Facilities”. I have retained a copy of this information and I am satisfied that I understand the purposes and processes Sarah Jeong is using. I understand that I can ask for any tape-recorded information provided by me to be deleted and that I can review the tape transcripts and add or delete any information on those transcripts.

Please tick the box(es) that represent(s) your decision.

I consent to participate in

☐

**Observation**

☐

**Interview**

I understand that my privacy will be protected and my confidentiality maintained. I also realise that I can revoke my consent and withdraw from the study at any time without any explanation.

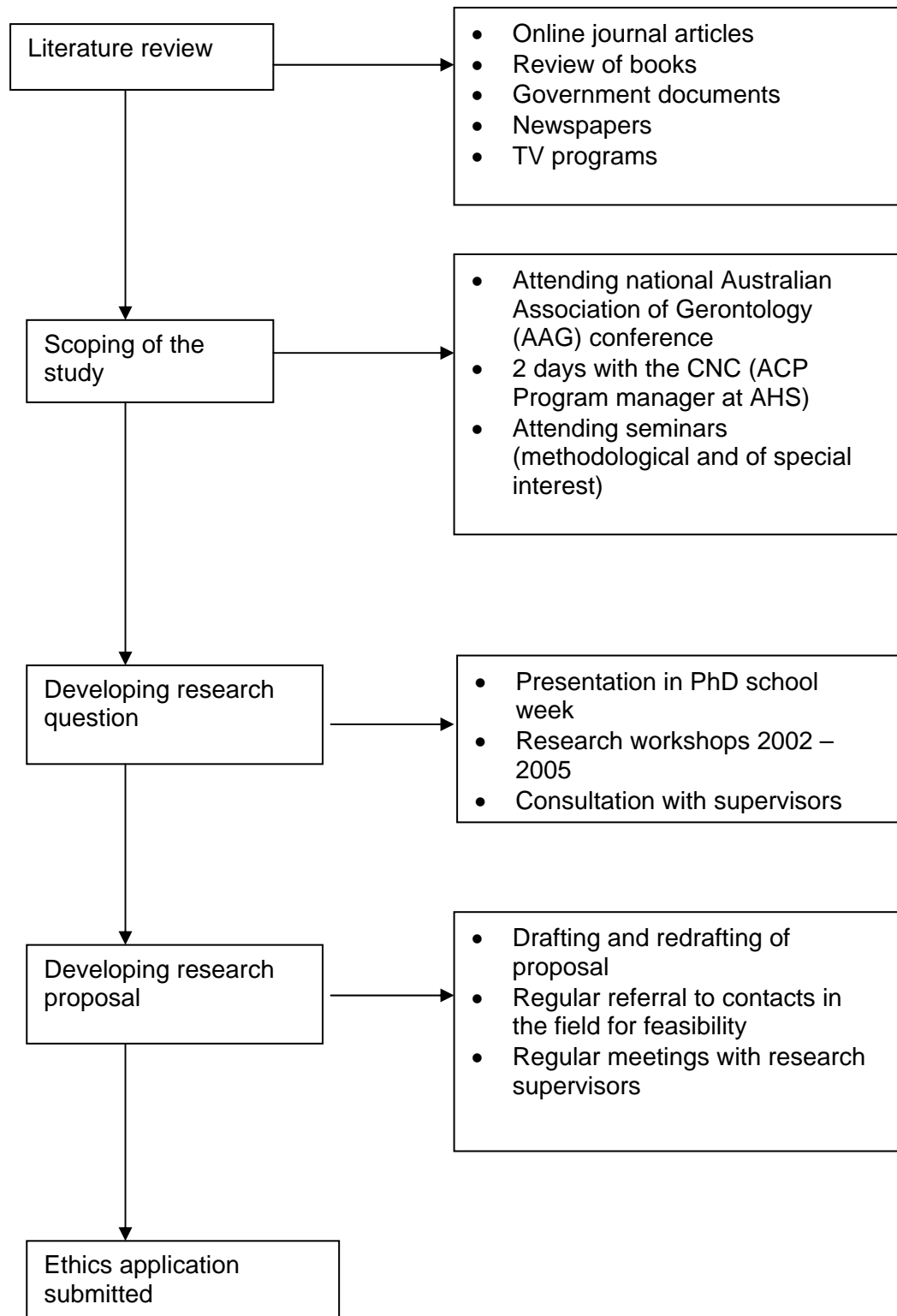
Print name .....

Signature.....

Date.....

Contact details.....

## Appendix 8. Preliminary work



## Appendix 9. Information letter for residents and family members

### Researcher

Sarah (Yeun-Sim) Jeong. RN., BN., MN., PhD Candidate.  
School of Nursing & Midwifery.  
University of Newcastle.  
Email: [Sarah.Jeong@newcastle.edu.au](mailto:Sarah.Jeong@newcastle.edu.au)  
Tel: (02) 4320-3941  
Fax: (02) 4320-2620

### Supervisors

Professor Margaret McMillan.  
Email: [Margaret.McMillan@newcastle.edu.au](mailto:Margaret.McMillan@newcastle.edu.au)  
Tel: (02) 4921-6005  
Fax: (02) 4921- 2020

Dr Isabel Higgins  
Email: [Isabel.Higgins@newcastle.edu.au](mailto:Isabel.Higgins@newcastle.edu.au)  
Tel: (02) 4921-6347  
Fax: (02) 4921-6301

### **Observation & Interview Information Statement for the Research Project: Residents and family members**

#### **Advance Care Planning (ACP) and Advance Care Directives (ACDs) in Residential Aged Care Facilities (RACFs) in Australia: A case study.**

<b>Researchers:</b>	
Professor Margaret McMillan (Chief Investigator) Faculty of Health The University of Newcastle	
Sarah Jeong (PhD Student) School of Nursing and Midwifery The University of Newcastle	Dr Isabel Higgins (Co-Supervisor) School of Nursing and Midwifery The University of Newcastle

You are invited to take part in the research project identified above which is being conducted by Sarah Jeong from the School of Nursing and Midwifery at The University of Newcastle. Sarah Jeong, who does not work in this nursing home, is conducting the research as part of her PhD under the supervision of Professor Margaret McMillan, and Dr Isabel Higgins.

You have been selected by the Director of Nursing in this nursing home to receive this information letter. She has provided me with a list of people who register with the Clinical Nurse Consultant responsible for Chronic and Complex Care in Nursing Homes who manages the Advance Care Planning Program.

### ***Why is the research being done?***

- The purpose of this research is to explore the experiences of residents, their family members, and nurses with Advance Care Planning (ACP) and Advance Care Directives (ACDs). ACP and ACDs are part of what is known as palliative care, which usually includes assessment of, and conversations

about a person's understanding of their medical history and condition, their personal values and preferences and the wishes of those close to them with regard to the kind of care they would like to receive.

- Information gained from this study will inform residents, families and nurses of the nature and scope of choices available to residents about their care as they approach the stage of decision-making around their care, which may or may not include "end-of-life" decisions.
- There is very little written about the topic of Advance Care Planning and Advance Care Directives and the views and experiences of residents, their family members, and nurses who provide care have not been adequately explored.

***Who can participate in the research?***

- I am seeking to involve residents and their families as participants in the research project.

***What choice do you have?***

- Participation in this research is entirely your choice.
- Only those residents and family members who give their informed consent will be included in this project.
- Whether or not you decide to participate, your decision will not disadvantage you in any way.
- If you do decide to participate, you have the right to refuse to discuss any issues you may not want to talk about and to withdraw from the project at any time without giving a reason.

***What will you be asked to do?***

Your involvement will include one or both of the following:

- i) **Being part of a period of observation of the Nursing Home by me over a three-month period.**
  - I will be observing the whole context of your Nursing Home with regard to the nursing management of end-of-life care.
  - I will be making notes to ensure that I have an accurate record.
  - The focus of my observation will be on the way the residents-family members-doctors-nursing staff inform, integrate and sustain Advance Care Planning into the care of residents.
  - I will also be observing how nursing staff respond to Advance Care Planning and Advance Care Directives.
- ii) **Participation in an interview**
  - If you decide to participate you will be asked to participate in one audio-taped interview conducted by Sarah Jeong and lasting up to one hour, and with your permission, it will be tape-recorded.
  - According to your wishes, the interview can involve you alone or your family members who give their consent to be interviewed.
  - During the interview you can turn the tape off at any time.
  - During the interview I will ask you to share your experience of decision-making about the nature and extent of your care.
  - The tapes will be transcribed and the data used for analysis.
  - You will be able to review the recording and/or transcriptions to edit or erase your contribution if required.

- Interviews will be conducted in private, at a date, time and place of mutual convenience.

***What are the risk and benefits of participating?***

- I cannot promise you any personal benefit from participating in this research other than an opportunity to have greater insight into aspects of your care. Insight gained in this study may be used to promote better plans of treatment for residents and families in the future.
- There are no risks that you will not receive the usual care or affect your involvement in Advance Care Planning in any way.
- Should you find the interview distressing, I will not proceed and will ensure an appropriate personal response to you and your family. I will at all times seek the assistance of staff who know you well.

***How will your privacy be protected?***

- All information that you provide will remain confidential.
- Within written records all names, including those of residential aged care facilities, will be altered and you will be asked to choose a pseudonym to replace your real name.
- Individual participants will not be identified in any reports arising from the project.
- An experienced person well-versed in the ethics of research will undertake the transcription of the audiotape. S/he will be required to sign a Promise of Confidentiality Agreement prior to the transcription.
- During the study computer records will be given a password and all names and contact details will be kept separate from records.
- While the study is underway, data will be kept on my home computer and backed up on a USB drive that will remain in my possession and be password protected.
- All paper records and tapes will be kept in a locked cabinet in my home.
- Only the researchers will have access to this data.
- At the completion of the interviews all participants' contact details will be destroyed.
- At the completion of the study all computer files will be stored with the paper records and tapes in a locked cabinet the School of Nursing and Midwifery for a period of five years.
- At the end of the five-year period, data on the USB drive will be erased, the tapes destroyed and paper based records shredded.

***How will the information collected be used?***

- Results from this study may be published both in my PhD dissertation and in scientific journals.
- Individual participants will not be identified in any reports arising from the research project.
- You are welcome to a copy of the transcript of your interview which will be available within two months, and/or a copy of the summary of the findings of the study.
- The findings will be available within two years and will be sent to you upon request. Please contact the researchers by e-mail, phone or mail to request the summary of findings.

***What do you need to do to participate?***

- If there is anything you do not understand, or if you would like to obtain further information about the project, you can contact one of the researchers.
- If you are willing to participate in the research project, please sign the attached consent form and return the form to the return box placed in the lounge or nurses' station.
- The forms in the return box will be collected on a daily basis for the next three weeks.
- Please be advised that only one interview will be conducted and selection of residents and family participants will occur through the Director of Nursing within the facility.
- The researcher will contact participants who consent to take part in an interview to arrange a mutually convenient date, time and place for the interview.
- Read this Information Statement and be sure you understand its contents before you sign the consent form.
- You are reminded that you can change your mind at any time and are not obliged to take part in the participant observation and/or interview if you do change your mind.

Thank you for considering this invitation.

Professor Margaret McMillan (Chief Investigator)  
Faculty of Health  
The University of Newcastle

Sarah Jeong (PhD Student)  
School of Nursing and Midwifery  
The University of Newcastle

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-104-0905. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02 49216333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au)).*

## Appendix 10. Consent form for observation and interview

I, ..... have received information from Sarah (Yeun-Sim) Jeong about her study “Advance Care Planning program in Residential Aged Care Facilities”. I have retained a copy of this information and I am satisfied that I understand the purposes and processes Sarah Jeong is using. I understand that I can ask for any tape-recorded information provided by me to be deleted and that I can review the tape transcripts and add or delete any information on those transcripts.

Please tick the box(es) that represent(s) your decision.

I consent to participate in

☐

**Observation**

☐

**Interview**

I understand that my privacy will be protected and my confidentiality maintained. I also realise that I can revoke my consent and withdraw from the study at any time without any explanation.

Print name .....

Signature.....

Date.....

Contact number (H).....

(M).....



## Appendix 11. Reminder letter for the consent form

### Researcher

Sarah (Yeun-Sim) Jeong. RN., BN., MN., PhD Candidate.  
School of Nursing & Midwifery.  
University of Newcastle.  
Email: [Sarah.Jeong@newcastle.edu.au](mailto:Sarah.Jeong@newcastle.edu.au)  
Tel: (02) 4320-3941  
Fax: (02) 4320-2620

### Supervisors

Professor Margaret McMillan.  
Email: [Margaret.McMillan@newcastle.edu.au](mailto:Margaret.McMillan@newcastle.edu.au)  
Tel: (02) 4921-6005  
Fax: (02) 4921- 2020

Dr Isabel Higgins  
Email: [Isabel.Higgins@newcastle.edu.au](mailto:Isabel.Higgins@newcastle.edu.au)  
Tel: (02) 4921-6347  
Fax: (02) 4921-6301

### **Dear residents, families and registered nurses,**

My name is Sarah (Yeun-Sim) Jeong and I am a Registered Nurse. I am also a PhD student at the University of Newcastle. As a requirement of my study, I am in the process of conducting a research project on "Advance Care Planning (ACP) program in Residential Aged Care Facilities (RACFs)". This letter is to remind you about the invitation to participate in this research project.

Three weeks ago consent forms for participant observation and interview were distributed to the residents, family members and registered nurses. If you have signed and returned in the box, thank you for your participation.

**This letter is to remind you that consent forms for observations and interviews will be collected by this Friday on a specified date. If you would like more information before you sign the consent form, please do not hesitate to contact me using the details on the top of this letter.**

If you are willing to participate in the observation and interview, please sign the enclosed consent form and put it in the envelope provided. The return box for the consent forms is placed on the desk in the nurses' station or in the lounge for the convenience.

If you did not receive the consent form or it has been misplaced, please contact the researcher while she is on the premises or by contacting the number on the top of this letter. Your participation is extremely important to the success of this research. For those who do not wish to participate in the interview, please disregard this letter. Thank you very much.

Yours sincerely,

Sarah (Yeun-Sim) Jeong (Student Researcher)

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-104-0905. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02 492 16333), email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).*

## Appendix 12. Information letter for RNs

### Researcher

Sarah (Yeun-Sim) Jeong. RN., BN., MN., PhD Candidate.  
School of Nursing & Midwifery.  
University of Newcastle.  
Email: [Sarah.Jeong@newcastle.edu.au](mailto:Sarah.Jeong@newcastle.edu.au)  
Tel: (02) 4320-3941  
Fax: (02) 4320-2620

### Supervisors

Professor Margaret McMillan.  
Email: [Margaret.McMillan@newcastle.edu.au](mailto:Margaret.McMillan@newcastle.edu.au)  
Tel: (02) 4921-6005  
Fax: (02) 4921- 2020

Dr Isabel Higgins  
Email: [Isabel.Higgins@newcastle.edu.au](mailto:Isabel.Higgins@newcastle.edu.au)  
Tel: (02) 4921-6347  
Fax: (02) 4921-6301

### ***Observation & Interview Information Statement for the Research Project: Registered Nurses***

### ***Advance Care Planning (ACP) and Advance Care Directives (ACDs) in Residential Aged Care Facilities (RACFs) in Australia: A case study.***

<b>Researchers:</b>	
Professor Margaret McMillan (Chief Investigator) Faculty of Health The University of Newcastle	
Sarah Jeong (PhD Student) School of Nursing and Midwifery The University of Newcastle	Dr Isabel Higgins (Co-Supervisor) School of Nursing and Midwifery The University of Newcastle

You are invited to take part in the research project identified above which is being conducted by Sarah Jeong from the School of Nursing and Midwifery at The University of Newcastle. Sarah Jeong, who does not work in this nursing home, is conducting the research as part of her PhD under the supervision of Professor Margaret McMillan, and Dr Isabel Higgins.

You have been selected by the Director of Nursing in this nursing home to receive this information from the list of registered nurses who have a minimum of two years' full-time or equivalent a work experience in caring for elderly residents.

### ***Why is the research being done?***

- The purpose of this research is to explore the experiences of residents, their family members, and nurses with Advance Care Planning (ACP) and Advance Care Directives (ACDs). ACP and ACDs are part of what is known as palliative care, which usually includes assessment of, and conversations about a person's understanding of their medical history and condition, their

personal values and preferences and the wishes of those close to them with regard to the kind of care they would like to receive.

- Information gained from this study will inform residents, families and nurses of the nature and scope of choices available to residents about their care as they approach the stage of decision-making around their care, which may or may not include “end-of-life” decisions.
- There is very little written about the topic of Advance Care Planning and Advance Care Directives and the views and experiences of residents, their family members, and nurses who provide care have not been adequately explored.

***Who can participate in the research?***

- I am seeking to involve registered nurses as participants in the research project.

***What choice do you have?***

- Participation in this research is entirely your choice.
- Only those nurses who give their informed consent will be included in this project.
- Whether or not you decide to participate, your decision will not disadvantage you in any way.
- If you do decide to participate, you have the right to refuse to discuss any issues you may not want to talk about and to withdraw from the project at any time without giving a reason.

***What you will be asked to do?***

Your involvement will include one or both of the following:

***i) Being part of a period of observation of the Nursing Home by me over a three-month period.***

- I will be observing the whole context of your Nursing Home with regard to the nursing management of end-of-life care.
- I will be making notes to ensure that I have an accurate record.
- The focus of my observation will be on the way the residents-family members-doctors-nursing staff inform, integrate and sustain Advance Care Planning into the care of residents.
- I will also be observing how nursing staff respond to Advance Care Planning and Advance Care Directives.

***ii) Participation in an interview***

- If you decide to participate you will be asked to participate in one audio-taped interview conducted by Sarah Jeong and lasting up to one hour, and with your permission, it will be tape-recorded.
- During the interview you can turn the tape off at any time.
- During the interview I will ask you to share your experience of taking care of elderly residents who are involved in the Advance Care Planning Program and Advance Care Directives.
- The tapes will be transcribed and the data used for analysis.
- You will be able to review the recording and/or transcription to edit or erase your contribution if required.
- Interviews will be conducted in private, at a date, time and place of mutual convenience.

***What are the risk and benefits of participating?***

- I cannot promise you any personal benefit from participating in this research other than an opportunity to have greater insight into aspects of care you provide. It is expected that the information gained from the project will increase the body of knowledge regarding the scope of opportunities for nurses to support residents and their family members in the Advance Care Planning process and Advance Care Directives, and will shed light on the nature and extent of nursing participation in those processes.
- There are no risks anticipated by participating in this research. Your decision to participate or not to participate will not affect you as a nurse or an employee in any way.
- Should you find the interview distressing, I will not proceed and will ensure an appropriate personal response to you.

***How will your privacy be protected?***

- All information that you provide will remain confidential.
- Within written records all names, including those of residential aged care facilities, will be altered and you will be asked to choose a pseudonym to replace your real name.
- Individual participants will not be identified in any reports arising from the project.
- An experienced person well-versed in the ethics of research will undertake the transcription of the audiotape. S/he will be required to sign a Promise of Confidentiality Agreement prior to the transcription.
- During the study computer records will be given a password and all names and contact details will be kept separate from records.
- While the study is underway, data will be kept on my home computer and backed up on a USB drive that will remain in my possession and be password protected.
- All paper records and tapes will be kept in a locked cabinet in my home.
- Only the researchers will have access to this data.
- At the completion of the interviews all participants' contact details will be destroyed.
- At the completion of the study all computer files will be stored with the paper records and tapes in a locked cabinet the School of Nursing and Midwifery for a period of five years.
- At the end of the five-year period, data on the USB drive will be erased, the tapes destroyed and paper-based records shredded.

***How will the information collected be used?***

- Results from this study may be published both in my PhD dissertation and in scientific journals.
- Individual participants will not be identified in any reports arising from the project.
- You are welcome to a copy of the transcript of your interview which will be available within two months, and/or a copy of the summary of the findings of the study.
- The findings will be available within two years and will be sent to you upon request. Please contact the researchers by e-mail, phone or mail to request the summary of findings.

***What do you need to do to participate?***

- If there is anything you do not understand, or if you would like to obtain further information about the project, you can contact one of the researchers.
- If you are willing to participate in the research project, please sign the attached consent form and return the form to the return box placed in the lounge or nurses' station.
- The forms in the return box will be collected on a daily basis for the next three weeks.
- Please be advised that only one interview will be conducted and selection of registered nurse participants will occur through the Director of Nursing within the facility.
- The researcher will contact participants who consent to take part in an interview to arrange a mutually convenient date, time and place for the interview.
- Read this Information Statement and be sure you understand its contents before you sign the consent form.
- You are reminded that you can change their mind at any time and are not obliged to take part in the research project if you do change your mind.

Thank you for considering this invitation.

Professor Margaret McMillan (Chief Investigator)  
Faculty of Health  
The University of Newcastle

Sarah Jeong (PhD Student)  
School of Nursing and Midwifery  
The University of Newcastle

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-104-0905. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02 49216333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).*

### **Appendix 13. Interview schedule for residents and family members**

The following are what the researcher intends to extrapolate from the data sets. However, these questions to participants are a guide only. They will not necessarily be asked in strict sequence but rather be prompts in an open-ended interview process.

1. Would you like to tell me about yourself?
2. What formal and informal processes are available for end-of-life (EOL) decision-making?
3. What does Advance Care Planning (ACP) mean to you?
4. What does Advance Care Directive (ACD) mean to you?
5. How does ACP and/or ACD affect your daily life in this nursing home? Describe what you are satisfied or not satisfied with ACP.
6. How and why has the ACP impacted on you as a resident/family member?
7. Tell me about your experience with ACP.
8. What perceptual difficulties and knowledge deficit do residents and families have? Which aspects of EOL care are important to residents and families, what they worry about in particular, what they most want, and what they fear? Do you have fears about your illness getting worse?
9. How would you describe your role as a family member in relation to ACP and ACD?
10. How do you feel about your role in ACP and ACD?
11. What are your concerns/worries in relation to ACP and ACD?
12. What would help for you to make this experience positive?

#### **Appendix 14. Interview schedule for the RNs**

The following are what the researcher intends to extrapolate from the study findings. However, these questions are a guide only. They will not necessarily be asked in strict sequence but rather be prompts in an open-ended interview process.

1. Tell me about your name and what your role is in this nursing home.
2. What formal and informal processes are available for end-of-life (EOL) decision-making?
3. Which aspects of EOL care are important to RNs, what they worry about in particular, what they most want, and what they fear?
4. Have you looked after the residents with Advance Care Directives? Can you give me some examples?
5. What does Advance Care Planning (ACP) mean to you?
6. What does Advance Care Directive (ACD) mean to you?
7. How does ACP and/or ACD affect your daily work as a nurse?
8. How and why has the ACP impacted on you as a nurse?
9. What do you think the impact/outcome of ACP is on residents?
10. What do you think the impact/outcome of ACP is on family members?
11. What do nurses think are the most effective ways to initiate, promote, implement and follow ACP and ACDs?
12. Why or why not do nurses assist older persons in preparing for the difficult choices surrounding dying?
13. What perceptual difficulties and knowledge deficit do residents and families have?  
Which aspects of EOL care are important to residents and families, what they worry about in particular, what they most want, and what they fear?
14. How would you describe your role in relation to ACP and ACD?
15. How do you feel about your role in ACP and ACD?
16. What do you think the implications of ACP and ACD for nurses?
17. How can we make the most out of ACP?
18. What would help for you to make this experience positive?
19. What perceptual difficulties and knowledge deficit do nurses have?
20. What are nurses' attitude, beliefs, comfort levels in relation to ACP and ACDs?

## **Appendix 15. Consent form for the transcriptionist**

I, ..... will be the only person who transcribes the data interviewed by Sarah (Yeun-Sim) Jeong and will consent to protect the privacy of both the interviewer and interviewees.

I understand all the ethical issues (confidentiality, anonymity, right to protection from harm) that could be drawn from the transcription. I will not disclose any of information to others with any personal details of the interviewees, which I may discover during transcription. I will also not copy any of the tapes interviewed for any other purpose.

Signature.....

Date.....



## Appendix 16. Audit trail Part A

### Codes, sub-categories, & categories

Codes	Sources *	References **	Sub-categories	Categories
Deterioration	8	24		Why ACP Implementation
Identify what they want	2	11		
Negative experience with hospital	4	5		
No suffering	4	8		
Right to decide	7	16		
ACP process	12	169		How ACP Implementation Process
Players in ACP implementation	7	45		
It's just me	3	23		RES Why ACD documentation
My right, my responsibility	3	14		
Negative experience in hospital	2	6		
Religious belief	2	4		
Save family responsibility	2	3		
Why prolong/No point	3	9		
No hospitalisation	9	19		Contents of ACDs
No tube feeding	5	6		
Not for resuscitation	5	6		
Palliative care and beyond	9	30		
Care is same as usual	2	3		RES outcomes of having ACDs documented
Essence of being	2	7		
QOC and PCC in RACFs	5	14		
Relief	4	17		
Family conflict	2	2		The outcomes of No ACD
Prolonging death	2	2		
Prolonging suffering	3	5		
Recurrent hospitalisation	5	2		
Acceptance	4	18		RES Perceptions/Experiences with ACP & ACDs
Difficulties with ACDs	1	11		
I have had a good life	2	5		
It's me. This is what I want.	1	1		
Worries and concerns	1	8		
Done the best for long time	2	6		FM Meaning/Experience of ACP & ACDs
Mum/Dad had enough. Use the resources better	2	5		
I wouldn't like it myself. No QOL	6	16		

Individual approach to initiate the ACP discussion	3	4		
It helps that I can revoke it	2	4		
It was the Nrs, not the Drs	4	4		
It's an honour and trust that I would do the right thing	6	11		
Keep dignity and QOL	5	8		
Need empowerment enabling	1	1		
No guilty feeling and not giving up	2	5		
No information on how dementia progresses	1	2		
No regrets but satisfaction & relieved	4	11		
Outcomes of ACP on FM by RNs saying	6	11		
The impact of current experience for future	4	7		
The impact of past experience with death and dying	5	11		
The impact of repetitive hospitalisation	2	5		
The involvement of hospital care team in ACP was good	2	3		
Wanted and needed back-ups from someone	6	22		
We wanted to be discussed and explained	8	15		
What is the point and it's not for me but for mum/dad	7	26		
Worries, concerns, and doubts	2	10		
Autonomy	2	4		RNs Meaning/Experience of ACP & ACDs
Back-up from FM & Nrs	3	9		
Direction for future	4	6		
Discussion	6	19		
Dying with dignity	3	6		
Experience & outcomes of ACP on RNs	8	23		
Making wishes	8	17		
Not euthanasia	5	9		
PCC	2	3		
Abusive	1	1		Feelings and emotions before transition
Angry	1	1		
Awful	2	3		
Burdensome	3	4		
Confronting	1	1		
Cruel	3	4		
Denial	1	1		
Difficult	2	4		
Guilt/giving up	1	3		
Sad	2	2		
Acceptance	7	14		Feelings and emotions after

Comfortable	7	11		transition
Happy	7	14		
Positive	5	9		
Proactive	1	2		
Reassurance	2	3		
Relief	8	10		
Satisfaction	5	6		
Surrender	3	6		
Back-ups from other FM and Nrs	1	1	FM Enhancing Factors	Factors influencing on the Transition
Dedication to care for long time (done the best for long time)	1	2		
It helps that I can revoke it	3	5		
Mum/Dad had a good life. Use the resources better	4	7		
Not for me but for mum/dad	7	13		
The impact of past experience with dying and death	5	11		
The involvement of hospital care team in ACP was good	3	6		
What is the point/No QOL/No dignity	2	2		
Lack of discussion	0	0	FM Inhibiting Factors	
Lack of explanation	1	1		
No back-ups	1	1		
No PCC	1	1		
I have had a good life. Use the resources better	2	5	Res Enhancing Factors	
It's just me. Essence of being	3	24		
My right, my responsibility	3	14		
Religious belief	2	4		
Why prolong/No point	3	9		
Difficult to understand medical aspects of treatment options	2	12	Res Inhibiting Factors	
Difficult to verbalise/express what I want into the terms that are valid	0	0		
Not being followed/Not being heard	1	9		
Selfishness of FM	1	2		
Back-ups from FM and other Nrs	3	10	RNs Enhancing Factors	
Clear direction for future	4	7		
Discussion	5	8		
Giving them choices/controls/autonomy	4	4		
Helping them to be essence of being	1	1		
It's not euthanasia	5	9		
Person-centred care	2	3		
Positive outcomes for the Res & FM	2	3		

Promote dignity & comfort	3	4	RNs Inhibiting Factors	
Providing reassurance to the Res & FM	1	1		
Respecting wishes consistent	3	4		
The involvement of hospital care team in ACP is important	2	3		
Culture of do everything	1	1		
Lack of discussion	3	7		
Lack of specificity	1	1		
No process in system	2	2		
Not being followed by FM	3	4		
Time limitation	2	2		
We don't want them back to hospital	1	1		
Advocating	1	6		
Broker	1	18		
Communicating	4	6		
Educating	4	3		
Empowering	1	5		
Enabling	3	1		
Facilitating	1	25		
Research	1	3		
Assessment	0	0	The managers	
Communication	8	5		
Coordination	4	8		
Designating & routinising for future	3	3		
Education	3	5		
Assessment	0	0	The RNs	
Communication	1	2		
Coordination	0	0		
Education	0	0		
Future functions desired	4	16		
Physical & behavioural care	5	15		
Research	0	0		

Sources \*: the number of participants who mentioned something related to the code

References \*\*: the number of excerpts related to the code

QOC: Quality of Care

PCC: Person-centred care

QOL: Quality of Life

FM: Family Member

Res: Resident

RN: Registered Nurse

## Appendix 17. Audit trail Part B

<div>Analysis process</div> <div>Data collected</div>	Reading, browsing, reflecting, coding, validating of codes and searching for emerging patterns in the data	Generating categories, sub-categories, and sub-sub-categories	Axial coding <ul style="list-style-type: none"> <li>• Relating subcategories to categories</li> <li>• Discovering paradigms &amp; patterns</li> <li>• Identifying relationships &amp; connections between categories</li> <li>• Making comparisons &amp; asking questions of the data in relation to the research questions</li> </ul>	Presenting/projecting the images of the phenomenon by developing narratives
(Res 2: Jill) I like to have things planned and ready ... I suppose <b>it is my nature, always has been.</b> What would be the use of it? Now I think now, the use of, I like to be useful. If I wasn't going to be of use to anyone, I am not interested. ... // ... So being useful ... means a lot to me.	It is me. Essence of being	RES Perceptions/Experiences with ACP & ACDs	Transitions occurred from negative to positive  Factors influencing on the Transition  Res Enhancing Factors	Narrative 32. 'Essence of being' was enhanced through ACP.
(Res 3: Morton) <b>I have always been disinterested in</b> the quantity of life but I do not want to be sick because I don't like being sick. I think anybody who wants to be sick must be out of their minds. Really I do. ... // ... If you don't get much out of life, what is the point? I really see no point so <b>that is me.</b>	It is me. Essence of being	RES Perceptions/Experiences with ACP & ACDs	Transitions occurred from negative to positive  Factors influencing on the Transition  Res Enhancing Factors	Narrative 32. 'Essence of being' was enhanced through ACP.
(Res 3: Morton) I really haven't because as I repeat, I can <b>see no point, absolutely no point ... in living ... when you really should be dead.</b> I mean to be alive and wanting to throw up for 24 hours a day. Nobody could say, you couldn't get a kick out of that unless you were really, really, really masochistic. Really masochistic, really top-grade masochism. I don't think that you could. So <b>to me it is only common sense.</b>	What is the point/ No point          It is me.	RES Perceptions/Experiences with ACP & ACDs	Transitions occurred from negative to positive  Factors influencing the Transition  Res Enhancing Factors	Narrative 36. I surrender. Why prolong? No point!       Narrative 32. 'Essence of being' was enhanced through ACP.

(FM 11: Trish) But I think <b>she'd hate</b> , she'd hate to think that she ended up like this. That's all I keep thinking about. And that's why the decision of no medication things like that, <b>knowing what she'd said to me</b> , you know.	Not for me but for mum/dad	FM Perceptions/Experiences with ACP & ACDs	Transitions occurred from negative to positive  Factors influencing the Transition  FM Enhancing Factors	Narrative 32. 'Essence of being' was enhanced through ACP.
(FM 22: Freddy) ... <b>difficult</b> . We feel that mum has suffered a great deal, we also feel that if mum as I was saying before, 20 years ago could look at herself today <b>she would not like to be in the position she is in</b> . She would want to go with dignity. And she was a nurse herself and <b>she was always a very pragmatic lady</b> . I think, what we are saying here basically is that if mum were to catch pneumonia or something like that and it was life-threatening and <b>it could possibly be saved by going to hospital taking her away from the comfortable situation she is in, we wouldn't really be advocating that</b> . We would rather she stayed here uninterrupted and just let things take their course. Give her the best possible care you can but no artificial extension of life even though I know that is a very grey area. <b>We just think that is in mum's best interest, what she would have liked. ... she wouldn't have wanted to prolong her life unnecessarily</b> just using modern technology as opposed to technology she was familiar with. We just don't think that would be the case.	Difficult  Not for me but for mum  Essence of mum's being  No hospitalisation  Not for me but for mum  Essence of mum's being	FM Perceptions/Experiences with ACP & ACDs   Contents of ACDs   FM Perceptions/Experiences with ACP & ACDs	Transitions occurred from negative to positive  Factors influencing the Transition  FM Enhancing Factors  Outcomes of ACP ACD/POT documentation   Transitions occurred from negative to positive  Factors influencing the Transition  FM Enhancing Factors	Narrative 32. 'Essence of being' was enhanced through ACP.   Narrative 25. 'No-hospitalisation' and 'NFR' because it doesn't do good, no benefit, no dignity.   Narrative 32. The residents' essence of being was enhanced through ACP.
(FM 16: Ray) I also thought that same way before she came into the nursing home because I felt like I was <b>giving up</b> on her then, you know, and <b>I sort of reasoned that out</b> . I said 'Well' at that time I sort of went through it and I thought well I'm not actually giving up because I've done as much as I can and um, I just can't ... you feel like you've <b>given up and just giving your mum away</b> , you know. That's not the	Giving up Reasoning/Justification   Giving up	FM Perceptions/Experiences with ACP & ACDs Transition	Transitions occurred from negative to positive	

<p>case really when you, when you go through it, when <b>you rationalise it in your mind</b>. I don't think that, I would think everybody would feel the same. I cannot imagine anybody not feeling that way in some way or the other, you know. That they'd given up. I suppose in a way you are ... //... Well see I don't feel so much like that anymore because <b>I've rationalised it</b> so ... It is still there, you still have that in the back of your mind but um ... I am much <b>more comfortable</b> with it, you know, than I was at first. Yeah, yeah I was very <b>uncomfortable</b> for some time, you know, <b>very uncomfortable</b> about it. ... // ... Well for that reason, <b>I thought I had given up</b>. ... // ... I still feel that way a bit but I also think well, you know, but <b>rationalise it</b>.</p>	<p>Rationalising</p> <p>Rationalising</p> <p>Comfortable Uncomfortable</p> <p>Giving up</p> <p>Rationalising</p>	<p>Transition</p> <p>Transition</p> <p>FM Perceptions/Experiences with ACP &amp; ACDs</p> <p>Transition</p>	<p>Feelings and emotions before/after transition</p>	
<p>(RN 26: Katrina)</p> <p>... which I guess would be in the domain of the DON or DDON. You know when you are ringing up for admission placement, if I was a DON, that's what I would be doing, I'd be really, really focusing on Advanced Care Directives. But I mean <b>I am not in that position. I am not in a senior management position</b> ... // ... If I was asked to do it I would definitely, but <b>I wouldn't at the moment</b>. I wouldn't until I was given the all clear, you know. I, no, I would always defer to um Suzie (DON)...I think management is quite, I think <b>they can do it really</b>. I mean it is not a real big nursing home and there's a DON and a DDON and an administration person. So I think it needs to, I think possibly where it needs to come from is from either the DON or the DDON. Because they are here all the time and they're doing the admissions. I mean you know, it makes sense that the person, or the first line of contact, they may not be doing the admissions but they are the first line of contact. So I think possibly that would be the place to start ... // ... in regard to Advanced Care Directives and Plan of Treatment as an RN at the moment ... probably</p>	<p>Initiation Communication Coordination</p> <p>Discussion</p>	<p>No initiation No communication No coordination</p> <p>No discussion</p>	<p>Passing the buck</p> <p>Minimal and limited roles</p> <p>No participation</p> <p>Roles and functions</p> <p>Knowledge &amp; skills</p>	<p>Narrative 47. Everyone is passing the buck with no understanding of each other's roles.</p> <p>Narrative 48. The RNs' roles in ACP were minimal and limited.</p>

<p><b>not as much as I should be.</b> I probably <b>should be asking more questions</b> ... You know, 'Does this person have an Advanced Care Directive?' The RNs on the floor, are the RNs on the floor interested in, are they doing...? Not really. <b>Maybe one or two might</b>, yes.</p>	<p>Initiation Discussion Communication</p>	<p>No initiation No discussion No communication</p> <p>Limited participation</p>		
<p>(RN 5: Heather) I would <b>ring Hanna</b> to get her out to visit. <b>We keep out of it</b> after that. It is between them. Other people, um ... well <b>you can't really initiate it</b>, someone has to come to you. They have been in a home for some time and <b>it's up to the relatives</b> really to approach. Maybe they would <b>approach the GP</b>. Sometimes they do that. I have been in the last little while when I do admissions, I usually do try to discuss it, to see if they have made any plans. ... // ... It is <b>not up to me to make any legal documentation about it but I would refer them then to Hanna</b>.</p>	<p>Referring Facilitation Brokering Initiation</p> <p>Referring Facilitation Brokering Referring</p>	<p>No initiation</p> <p>Limited participation Limited contribution</p>	<p>Roles and functions</p> <p>Knowledge &amp; skills</p>	<p>Narrative 47. Everyone is passing the buck with no understanding of each other's roles.</p> <p>Narrative 48. The RNs' roles in ACP were minimal and limited.</p>



**Appendix 18. Framework of questions to explore the experience of residents, family members, and RNs with ACP**

1. What does ACP/ACD/POT mean to you?
2. What were the decisions you included in the ACDs/POT? What was the content of ACDs/POT documented?
3. Why did you make the decisions you made in the ACDs/POT?
4. What went through your mind while you were involved in ACP and in making decisions for yourself or your mum/dad?
5. How did you feel about these decisions (those you made in ACDs/POT)?
6. What/how did you feel while you went through the processes of developing the ACDs?
7. Did you have any difficulties/worries/concerns with/during the ACP process? What were they?
8. How did you cope with the difficulties/worries/concerns? What helped you to go through/overcome the difficulties/worries/concerns?
9. How do you feel now that the ACDs/POT has been documented?

## Appendix 19. The exemplar and the roles and functions of nurses in ACP

Exemplum 1: The story of Morton	CNC	Managers	RNs
<p>Morton's story was chosen to demonstrate how a competent older person who expressed his wish to be in control of end-of-life care became involved in ACP process and in documenting his wishes in ACDs. The CNC played a crucial role as a facilitator in the process.</p> <p>Morton was referred to Hanna by the RN Kim from the community cardiology team. Hanna had a brief chat with Kim on the phone and found that Morton was a 94-year-old man with end-stage prostate cancer metastasised in bones. He had heart attacks twice and Dr Rich inserted a pace-maker for him several years ago. He was seen by an RN Kim for a while but then he was told that there was nothing they could do for him. He had a lung problem, pleural effusion which was caused by the end-stage heart failure. Hanna was told that Morton has accepted that he was at the end stage of heart failure and expressed his wish not to be resuscitated if he had a heart attack. Kim thought that his wish needed to be explored further by a qualified person in this area. As Kim remembered Hanna's education session two years ago about decision-making at the end of life, substitute decision-maker, and consent she contacted Hanna for a review of Morton's wish.</p> <p>Hanna rang Morton to introduce herself and to arrange a home visit. She also reviewed his hospital files with his permission. Hanna asked him for his permission to inform his GP (Dr. James) about his willingness to discuss end-of-life treatment options with her and how it was going to proceed with her. Morton gave Hanna the permission to do so. Morton did not know at this stage what Hanna could do for him although he welcomed Hanna to his space. Hanna also contacted the manager to let her know that she was coming to see Morton. She was told that Morton had a close relationship with his niece who lived in country NSW and who was the Person Responsible (PR) for him.</p> <p><u>During the initial visit</u>, Hanna used MMSE and GDS to assess his cognitive impairment and depressive thoughts. He was proved to be cognitively alert, as he</p>	<ul style="list-style-type: none"> <li>• Referral</li> <li>• Deterioration: Situation in need of ACP</li> <li>• Informing,</li> <li>• Educating staff,</li> <li>• Promoting knowledge &amp; skills of staff,</li> <li>• Retrieval of information: medical history.</li> <li>• Information acquisition via verbal &amp; written report &amp; observation</li> <li>• Initiating,</li> <li>• Discussing,</li> <li>• Processing clinical judgement</li> <li>• Leading initiation of discussion.</li> <li>• Current information:</li> </ul>	<ul style="list-style-type: none"> <li>• Collecting information through admission kit: PR was appointed and kept in contact.</li> </ul>	<ul style="list-style-type: none"> <li>• Conveying messages in relation to ACP</li> <li>• Observing, measuring, &amp;</li> </ul>

<p>scored 29 out of 30 in MMSE. The result of his GDS suggested that he was at low risk for depression as he did not have any depressive thoughts.</p> <p>His other medical diagnoses included NIDDM, Macular Degeneration, hearing impairment, and weight loss. He lost 20 kilograms between December 2005 and August 2006. He lost appetite dramatically and supplements like Sustagen made him sick. Nausea has been a big problem but since Dr James changed his medication it settled a bit. His bowel motion caused him grief sometimes so he took 2 Coloxyl senna at night. He was told that the maximum dose was 3-3-3 a day so there is a plenty of room to move. He now took 2 in the morning and 2 at night. Morton said that his Prostate Specific Antigen (PSA) had gone through the roof at one stage so he thought about a bone scan but then he declined to do bone scan as he, his family and his doctor thought there was no point in doing it as the result would have been metastasised in other parts of body which was expected, and they wouldn't be able to do much as he was at end-stage heart failure and it may not be tolerable. Morton said the biggest problem was lethargy, he said he was very lethargic. His nausea was an issue but Stematil helped and it was suggested that he take regularly 2-3 times a day and not to wait until nausea got worse. He mentioned that he was short of breath even with very limited exertion, for example, from his bed to downstairs to get milk. (He takes a lift to come downstairs as he resided on 2<sup>nd</sup> floor).</p> <p>Morton grew up in a strong Irish Catholic background. There were 9 siblings and he was the second last. He became a lawyer but hated it. He did it for his mother. His uncle had a practice in Sydney so he took over the practice for a while but after his mother passed away he went back to England and became a dressmaker. He had a dress shop in Sydney which was still being run by his friend. He lived in a private low-care facility over the last 2 years. He had never married and no children.</p> <p>His sister passed away in March 2006 and it was a shock to Morton and it was even more shocking to see the way she died. Morton said that she died in a horrific way and he didn't want that happen to him. He became teary and his eyes were filled with tears when he talked about his sister who died in the hospital with lots of tubes and catheters, drooling, cognitively impaired, and incontinent. He said she was a beautiful girl and that lady who was lying in the hospital bed drooling and with tubes was not his sister and he didn't want to see her like that. So he didn't visit her any more. He didn't want to be like that. He also had a bad experience at A&amp;E at St Mario Hospital when he had a fall. He was left in the trolley with excruciating pain for 24 hours and they couldn't get him out of the hospital quick enough next day. He felt it was terrible to be treated like that.</p>	<p>pathological, physiological, functional, psychological, neurological.</p> <ul style="list-style-type: none"> <li>• Retrieval of information: cultural, spiritual, familial, values in life, essence of being</li> <li>• Gathering new information: legal,</li> <li>• Retrieval of information: essence of being, values in life, familial</li> <li>• Gathering new information: preference of care</li> <li>• Retrieval of information: essence of being,</li> </ul>		<p>assessing of any changes in pathological, physiological, psychological, functional spiritual aspects</p> <ul style="list-style-type: none"> <li>• Maintaining current functions</li> <li>• Providing therapeutic agents</li> <li>• Enhancing comfort</li> </ul>
--	---	--	--

<p>Morton had such a lovely character. He loved his life and friends. He has lived his life to the full. He didn't want to feel sorry for himself or to get sick. He knew the fact that life could throw nasty things but also knew how to manage those and how to live life to the full. He described himself as 'quite eccentric but such a beautiful way'. He said that his life has been fabulous and interesting and had no desire to linger on. His eyes sparkled and his sense of humour was still alive and he liked to make people laugh. He was such an elegant person. He always presented himself well with a great sense of humour, attitude and gestures.</p> <p>Morton said that the CNC Hanna came to show him paradise with ACDs. He said that it was all right with him to talk about dying as he thought it was a part of living. Morton was considered as competent to document his own ACDs and was willing to go ahead. Hanna told Morton to think about what the important things were in his life, what quality of life would mean to him, and what would be an intolerable situation to him. She made another appointment with Morton.</p> <p><u>During the second visit</u>, Hanna went through, 'Value Clarification' form with him to assess what he valued in his life, how he saw treatment options at the end of life, and what the intolerable situations were for him.</p> <p>Hanna explored Morton's thoughts about a number of items. First of all, she asked Morton how important it was for him to be functionally independent to maintain his quality of life. He found eating, drinking, and grooming were not important but walking, bathing, toileting were somewhat important at functional level to maintain his quality of life. He considered being able to recognise friends and family members, being able to talk and be understood, thinking clearly, socialising activities were very important and necessary in his quality of life. Being free from symptoms like pain, discomfort, nausea, diarrhoea, and shortness of breath were very important for Morton to feel that he had quality of life.</p> <p>Hanna explored Morton's thoughts about 'Hope for recovery or natural death'. She read the statement in the form which was 'If I were very sick, told that I was to die soon, and that there was no reasonable hope that I would regain a quality of life acceptable to me ...' Morton answered 'Yes, I would expect to be given care and treatment for pain or discomfort even when such care might shorten my life, make me feel like not eating, slow down my breathing, or be habit forming'. He answered 'No' to the statement that 'I would want all possible treatments even though my doctors don't</p>	<p>values in life</p> <ul style="list-style-type: none"> <li>• Processing clinical judgement</li> <li>• Gathering new information: Value clarification, preference of care.</li> <li>• Initiating</li> <li>• Discussing.</li> <li>• Gathering new information: Value clarification, preference of care</li> <li>• Initiating</li> </ul>		
--	---	--	--

<p>think they could help me, because I would hope for a miracle to prolong my life’.</p> <p>Morton was told the statement ‘If I were in a coma and the doctors thought I only have a slight chance of returning to my normal health’ and was given an opportunity to answer ‘yes, no, or not sure’ to the following three statements. He answered ‘No’ to the statement that is ‘I would want to be kept alive indefinitely, because I would still hope for a new medical development that would help cure me’. Morton answered ‘Yes’ to the statements that are ‘I would not want to be given a treatment just to keep me alive when I had a condition that would cause me to die soon’, and ‘I would not want to be given a treatment to keep me alive if I had a condition so bad (including substantial brain damage or brain disease) that there was no reasonable hope that I would regain a quality of life acceptable to me’.</p> <p>Hanna explored Morton’s personal, ethical, or spiritual beliefs he wants respected in decision-making about life-sustaining treatments. It was found that he does not believe that ‘it is always wrong to withhold (not start) treatments that could keep him alive’. He disagreed that ‘it is always wrong to withdraw (stop) treatments that could keep me alive after they have been started’. He did not think that ‘it is wrong to withhold (not provide) nutrition and fluids given through tubes, even if he is terminally ill or in a coma’. In other words, he did not want tube feeding. He did not wish to receive a blood transfusion or any blood products such as plasma or red blood cells, not because of his religious belief but because of his unwillingness to be kept alive. He mentioned that he would not want to put any one of his close family members out when making health-care decisions on his behalf. He did not want alternative medicines. He explained that his religious beliefs were based on Catholicism but did not want advice from the Father at the Hospice Unit.</p> <p>As noted above, some of the statements were double negative and it could be confusing if Morton answered ‘No’ to those double negative statements. Therefore, Morton had to clearly understand what he was asked for and what he answered. Hanna made sure that he expressed his thoughts and wishes with his own words and by repeating the same questions until he understood. Hanna asked him a number of questions about how he lived, what he was interested in, what he believed as milestones in his life, if he had any crisis in his life, how he made important decisions in life, etc. The process of the visits progressed step by step based on Morton’s physical, emotional, and psychological process to take in the concept of ACDs. He mentioned that he did not have any problem understanding or discussing end-of-life treatment options. In fact, he said that he wanted to make his wishes legally valid. He</p>	<ul style="list-style-type: none"> <li>• Discussing.</li> <li>• Gathering new information: Value clarification, preference of care,</li> <li>• Initiating,</li> <li>• Discussing.</li> <li>• Gathering new information: Value clarification, preference of care,</li> <li>• Initiating,</li> <li>• Discussing.</li> <li>• Processing clinical judgement</li> <li>• Gathering new information: Value clarification, preference of care,</li> <li>• Initiating,</li> <li>• Discussing,</li> <li>• Supporting the person</li> </ul>		
--	--	--	--

<p>had clearly expressed what he valued in life and what he thought about end-of-life treatments. Hanna gave him enough time to think, explanation to make things clear, and prompts to help him understand if necessary. Morton was a competent, intelligent, and sensible man who believed that documentation of ACDs truly was what he wanted to do.</p> <p>His close friend, Mrs S was present during this initial visit to support him but had no influence on Morton's thoughts and wishes. Hanna informed him that his PR needed to know what they discussed today and she would contact his niece with his permission. Morton was given a chance to think about what would be tolerable/intolerable situation for him until the third visit in 3 weeks.</p> <p><u>During the third visit</u>, Hanna commenced the conversation with how he had been and if he had thought about what would be the tolerable/intolerable situation for him. Morton said that he had thought about it and he was ready to write down his thoughts with the help of Hanna. Morton made a statement of an intolerable situation that was when his directive would take an effect. He said that if the time comes when "I am incontinent of faeces or I am unable to recognise my friends and this situation is irreversible I request the following". Morton did not want CPR under any circumstances. He also stated that "Please do everything to keep me comfortable and free from pain, even though I may have indicated that I do not want to have certain treatments, I understand that these may be necessary to keep me comfortable".</p> <p>Hanna discussed with Morton the four levels of care which are palliative, limited, active and intensive care in cases of him having reversible and irreversible illness. In this discussion Hanna carefully explained what it all meant and what it could indicate to him. She has given him a number of scenarios to help him understand the concept of each level of care and what would be the possible consequences of the decisions he may make. It was noted that this discussion process was essential in order to help him fully informed and involved in decision-making. Hanna mentioned that she would not go any further if the individual did not want to know any more. She emphasised that ACDs could not be done with boxes to tick but she had to go through discussion process with everyone involved. If there was any concern or doubt then it should be</p>	<p>(psychological, spiritual)</p> <ul style="list-style-type: none"> <li>• Leading initiation of discussion,</li> <li>• Developing ACDs,</li> <li>• Enabling &amp;</li> <li>• Empowering to make decisions.</li> </ul> <ul style="list-style-type: none"> <li>• Developing &amp;</li> <li>• Planning ACDs,</li> <li>• Enabling &amp;</li> <li>• Empowering to make decisions,</li> <li>• Promoting knowledge.</li> </ul> <ul style="list-style-type: none"> <li>• Developing &amp;</li> <li>• Planning ACDs,</li> <li>• Enabling &amp;</li> <li>• Empowering to make decisions</li> <li>• Promoting knowledge,</li> <li>• Informing,</li> <li>• Educating,</li> <li>• Discussing,</li> <li>• Supporting the person and the family.</li> </ul> <ul style="list-style-type: none"> <li>• Developing &amp;</li> <li>• Planning ACDs,</li> <li>• Enabling &amp;</li> <li>• Empowering to make decisions</li> </ul>		
---	---	--	--



<p>that he had a good life and enjoyed his life very much, however, did not have the intention of accepting any invasive and aggressive treatment that may hinder nature's course. He clearly explained that he had always lived his life to the full and simply resisted anything that was not him. He did not see the point of being kept alive when he did not recognise his dear family and friends, when he was not able to think, when he became incontinent of faeces, and when he was not able to engage in social activities. Another reason for documenting ACDs was that he observed how his sister died in the hospital because of end stage dementia. This experience has impacted on Morton to decide that he wanted to prepare for his dying process and death.</p> <p>After all the discussion Hanna read through what had been discussed and documented to Morton and his niece. They agreed that what was documented was the same as what he wanted. Morton signed his ACDs. His niece could not be a witness as she was the beneficiary of his will. His close friend Mrs S read her responsibility as a witness, that was 'I verify that the person signing this document does so voluntarily and appears to understand the general nature and effect of the document. They did so without being placed under pressure. They were not coerced. This person is not related to either myself or my employer. Neither I nor my employer is a beneficiary in the will'. Mrs S then signed the ACDs as a witness. It was explained to Morton that the content can be revoked if he changed his mind. Otherwise it will be reviewed every six months or following an event such as an acute episode of illness. A copy of his ACDs would travel with him in case he was send to hospital or hospice.</p> <p>Hanna told them that the ACDs documented would be sent to his GP with his permission as it was essential that his GP knew what Morton wanted and what he did not want with regard to end-of-life treatments. Dr James has been supportive of Morton's willingness to document ACDs and promised his cooperation in respecting his wishes in the ACDs. Hanna mentioned that it was impossible to keep Morton's end-of-life wishes without Dr James's support and cooperation, as he would be the one who would prescribe medication, treatment, and might send Morton to the hospital against his documented wishes.</p> <p>The PR was assured of what Morton wanted when he could not speak for himself at the end of life and what her role was. Morton and the PR were given support throughout the process and all the questions were discussed and addressed openly.</p>	<ul style="list-style-type: none"> <li>• Promoting knowledge,</li> <li>• Discussing,</li> <li>• Informing,</li> <li>• Supporting the person and the family.</li> </ul> <ul style="list-style-type: none"> <li>• Conveying,</li> <li>• Reporting, &amp;</li> <li>• Recording messages in relation to ACD,</li> <li>• Informing.</li> </ul> <ul style="list-style-type: none"> <li>• Conveying,</li> <li>• Reporting, &amp;</li> <li>• Recording messages in relation to ACD,</li> <li>• Informing,</li> <li>• Supporting the person.</li> </ul> <ul style="list-style-type: none"> <li>• Informing,</li> <li>• Conveying,</li> <li>• Recording, &amp;</li> <li>• Reporting messages in relation to ACDs.</li> </ul> <ul style="list-style-type: none"> <li>• Processing clinical judgment,</li> <li>• Developing</li> </ul>	<ul style="list-style-type: none"> <li>• Conveying,</li> <li>• Recording, &amp;</li> <li>• Reporting messages in relation to ACDs.</li> </ul>	<ul style="list-style-type: none"> <li>• Conveying,</li> <li>• Recording, &amp;</li> <li>• Reporting messages in relation to ACDs.</li> </ul>
--	--	---	---



<p>Morton had expressed concerns that he might be transferred to the hospital and left in the corner of the A &amp; E without being seen by a doctor as he had experienced before. He was adamant that he did not want to be transferred to a hospital but wanted to be cared for where he was at now regardless of reversible and irreversible illness. Hanna explained to Morton that she would inform everyone involved in his care about his ACDs and his chart would be marked with a distinctive colour.</p> <p>Hanna informed the staff at the facility about Morton's ACDs and his ACDs were filed at the front of his file. The DON was informed of the outcomes of ACP with Morton. A note was made by the DON in the RNs' communication book to inform all the RNs. The RNs informed other staff members during hand-over.</p> <p>Hanna ensured that the ACDs documented met the four standards developed by the Department of Health in NSW: competency, currency, specificity, and witness. She mentioned that it was important that ACDs documented met these standards to make the ACDs valid and to take an effect in practice, even if the ACDs were not legally bound in NSW.</p>	ACDs.		
---	-------	--	--

<b>Exemplum 2: The story of Mary, Milson and Laura</b>	<b>CNC</b>	<b>Managers</b>	<b>RNs</b>
<p>The following example was chosen, as it is different from Morton's story. Morton was competent and was able to verbalise and document what he wanted at the end of life. However, Mary was not able to think or speak for herself, which required her PR to document her wishes in POT.</p> <p>Hanna had a call from the DON of a facility to review Mary's case. Mary's family was concerned that Mary was deteriorating due to the recent hospitalisation for aspiration pneumonia. The family was contacted by Hanna and made an appointment to meet and discuss. Hanna reviewed Mary's hospital file with permission from the family before she came to see them.</p>	<ul style="list-style-type: none"> <li>• Referral</li> <li>• Deterioration</li> <li>• Situation in need of ACP</li> </ul>	<ul style="list-style-type: none"> <li>• Conveying messages in relation to ACP,</li> <li>• Collecting information through admission kit,</li> </ul>	

<p>Mary who was a 92-year-old, has been living in a high-care facility since January 2006. She never married and used to live in her own house with her sister. Her sister passed away and her dementia worsened to level at which she could not look after herself at home. Her medical prognoses included Alzheimer's dementia, chronic lymphatic myeloid leukaemia, osteoporosis, hearing loss, and macular degeneration. Mary had a brother called Milson who was 90 years old and a niece called Laura who was in her 40s. Laura was Milson's daughter and has never married. Laura lived with Milson in a house privately owned and looked after her father Milson as he had a number of medical problems including arthritis, NIDDM, MI, MD, and hearing impairment. Milson and Laura were legally appointed 'Enduring Guardians' for Mary.</p> <p>Mary has recently been hospitalised for aspiration pneumonia. Milson and Laura were concerned that Mary has not been able to walk and seemed to be more confused since then. The nursing staff noticed more of Mary saying 'Hello, hello, thank you, thank you'. The staff were conscious that Mary has completed 2 courses of antibiotics recently and tried to make her comfortable as much as they could. Milson told that Mary accepted her situations in the nursing home but she occasionally said that she wanted to come home with him. Laura went to see Mary the day before Mary was sent to the hospital and Mary said that 'let's get out of here'. She repeated it again while she was in the hospital. They talked to the DON in the high-care facility about Mary's deterioration and asked for advice about their unwillingness of hospitalisation in future. Therefore, Hanna was contacted for ACP.</p> <p><u>During the first visit</u>, Hanna introduced herself and explained her role was to follow-up people who had recently been hospitalised and to help if further hospital services were required. She said that she visited people in nursing homes to help older people and families plan ahead for the future. Hanna described her role in general as people did not understand the exact title of her position, which was 'Clinical Nurse Consultant in Chronic and Complex Care in Nursing Homes'. Laura said that she was glad that Hanna was sent from the hospital and the hospital has not given up on Mary. It was interesting to note the ambivalence experienced by Milson and Laura. They did not want to send Mary to the hospital in future as they believed that hospitalisation did not do any good for Mary. However, they needed someone from the hospital to confirm that their decision not to send Mary to the hospital did not mean that they abandoned Mary in a state of pain or suffering. They said that Hanna eased their feeling of guilt over the decision not to send Mary to the hospital and gave them comfort in searching for what was best for Mary.</p> <p>Hanna initiated conversation with Milson and Laura by asking what kind of person</p>	<ul style="list-style-type: none"> <li>• Retrieval of information: medical history, social, familial.</li> <li>• Gathering new information: legal.</li> <li>• Current information: pathophysiological, psychological, functional, neurological.</li> <li>• Informing the family,</li> <li>• Supporting the family (psychological, spiritual),</li> <li>• Counselling,</li> <li>• Retrieval of</li> </ul>	<ul style="list-style-type: none"> <li>• Supporting of the family,</li> <li>• Initiating ACP,</li> <li>• Advocating.</li> </ul>	<ul style="list-style-type: none"> <li>• Observing,</li> <li>• Measuring, &amp;</li> <li>• Assessing of any changes in pathological, physiological, psychological, functional, spiritual aspects</li> <li>• Maintaining current functions,</li> <li>• Providing therapeutic agents (eg, antibiotics),</li> <li>• Enhancing comfort.</li> </ul>
--	--	---	--

<p>Mary was, how she lived her life, and what she valued in life. Mary was one of six children. She was very devoted Catholic. She fell in love with a man but he married another woman. Mary was never interested in a man since then. Mary ran a hair salon for 40 years. Milson told Hanna that Mary was very successful hair dresser as she was very good with people. Mary used to live with one of her sisters in another town but moved into Milson's house since the sister passed away and her health was deteriorated to the stage that she couldn't look after herself. Laura used to look after Milson and Mary but then it became too much for Laura to take care of two dependent older people on her.</p> <p>Hanna asked Milson and Laura about how they felt about what was going on with Mary. They said that they were concerned about what they were told in the hospital. Milson and Laura were briefly told in the hospital that Mary may make frequent hospital trips from now on and it was part of the dementia process. They were told to be prepared for what may happen in the future. Milson and Laura wanted to know more about the prognosis of dementia and how it would affect Mary and themselves.</p> <p>Hanna explained to Milson and Laura the signs and symptoms of end-stage dementia. Hanna told them that dementia was a terminal brain illness which was irreversible at present. It was her brain not being able to coordinate walking. It was not the legs disease, but the brain illness. It was the same for the swallowing, chewing, and every function in the body. Dr Thompson confirmed that Mary was incapable of consenting medical treatment as she could not understand the nature and the effect of the treatment. She could not indicate whether or not she consented. Milson and Laura told Hanna that they were the joint 'Enduring Guardians' of Mary and they were appointed while Mary was still able to do so. It was clear that Milson and Laura were the substitute decision-makers for Mary by law. Hanna read out their rights and responsibilities as decision makers. Milson and Laura were to know and understand; what the proposed treatment was, what the risks and alternatives were, that they could say 'yes', or 'no' to the proposed treatment, and that they could seek a second opinion. They were also informed that they cannot consent to special medical treatment, and consent to a treatment if the patient objects to the treatment.</p> <p>Laura raised the issue of Mary's hearing impairment and how important it was for Mary to be able to hear. Laura said that Mary would want to have special treatment for her hearing. Hanna explained again what it meant by 'special treatment' in the definition by the Guardianship Board. It meant such as sterilisation operations, terminations of pregnancy, and experimental treatment. Laura and Milson then</p>	<p>information: essence of being, values in life, social, economical, familial, spiritual, • Processing clinical judgement.</p> <p>• Leading initiation of discussion, • Processing clinical judgement.</p> <p>• Gathering new information: legal clarification, • Developing. • Planning POT, • Discussing, • Counselling, • Informing, • Educating the family, • Promoting knowledge.</p> <p>• Promoting knowledge, • Discussing, • Educating family,</p>		
---	---	--	--





<p>aspiration pneumonia again. Milson and Laura wanted 'Limited Care' for Mary in the case of reversible illness, which did not include elective surgery except for comfort or pain relief. They stated 'please provide care in the facility where possible and refer to PACS for management as required'. They wanted 'Palliative Care' for irreversible illness by stating 'provide care and treatment in the facility with referral to palliative care service where necessary'. Hanna confirmed that Milson and Laura would do anything and everything to make Mary comfortable and pain-free. At this point, Milson suddenly wanted to ensure that he was not denying anything. Laura also said that we were only saying 'no' to CPR and tubes ... and Mary would not want oxygen.</p> <p>Hanna realised that Milson and Laura needed confirmation and support from her that they were not hastening death or abandoning Mary by refusing treatment. Hanna explained that if Mary pulled it off then we would have to restrain her and put that oxygen mask back on. Hanna pointed that, however, it was necessary to think about to what extent and at what stage you would go ahead by holding her hands down and force the treatment that she did not want. It was also important to consider how you would provide care for her when she was confused and made herself distressed because of the unwanted treatment. Hanna went on to say that Mary's thinking ability was impaired and she could not think what we thought. Hanna explained that, for example, Mary, unlike us, could not think that she had to have this drip because she had chest infection, and the drip would help because it gave her antibiotics, and that would fix the infection. Milson agreed that Mary would not be able to understand and process all that explanation at this stage. Laura added that Mary had been a reasonable person and she would not see the point of having something that would not bring back the life she used to enjoy. Hanna looked at the faces of Milson and Laura. Hanna felt that they were comforted with the assurance from her and ready to move on to next issue.</p> <p>Hanna asked Milson and Laura if Mary would have wanted 'Active Care or Surgical treatment' in case of reversible or irreversible illness. Laura asked what it meant by 'Active Care'. Hanna explained that it includes transfer to hospital, all possible treatment including operations, and breathing machine (ventilator) used only for the purpose of surgery, or recovery from surgery. Laura said that it was hard for her to decide now as she was not able to comprehend what the situation would be like. Hanna reassured that she could discuss it as required. Then Laura was asked what Mary would have said about 'Intensive Care' which includes all possible means of life support including surgery, transplant, dialysis, and ventilator support. Laura said that it was not an option for Mary. Milson said that Mary would say that 'it was enough</p>	<ul style="list-style-type: none"> <li>• Promoting knowledge,</li> <li>• Enabling, &amp;</li> <li>• Empowering to make decisions.</li> </ul> <ul style="list-style-type: none"> <li>• Supporting the family: psychological, spiritual,</li> <li>• Promoting knowledge,</li> <li>• Enabling, &amp;</li> <li>• Empowering to make decisions,</li> <li>• Discussing,</li> <li>• Developing, &amp;</li> <li>• Planning POT.</li> </ul> <ul style="list-style-type: none"> <li>• Developing,</li> <li>• Planning POT,</li> <li>• Promoting knowledge,</li> <li>• Enabling, &amp;</li> <li>• Empowering to make decisions,</li> <li>• Supporting the family: psychological,</li> </ul>		
---	--	--	--



<p>continue with her current feeding regime'. Hanna wrote 'no' to IV and tube feeding. Milson and Laura confirmed that Mary was not to have a tube into her stomach or through the nose.</p> <p>Hanna read some concerns in Laura's face. Hanna explained that with a nasogastric tube, a lot of people with dementia did not know what it was and they just pulled it out. She provided Milson and Laura with the result of research. Some researchers have done scores on people who were capable and sensitive about what the most painful thing they had among blood test, tube in nose, and a catheter in bladder. People rated nasogastric tube as the most uncomfortable thing they could have. It hurt going in and was weird to keep it in. People gagged and coughed. It was not a comfortable procedure. Laura and Milson did not think that Mary would want to go through all that at this stage of her life just to keep her alive without being able to enjoy the food. Hanna asked them again if it would be what Mary would want or what they would want. They looked at each other and clearly stated that Mary would not want all that.</p> <p>All of sudden, Laura asked a question "are we jumping the gun?" Hanna noted that Laura was concerned again about the whole process of documenting POT in advance. Hanna asked Laura what she meant by 'are we jumping the gun?' Laura said that she did not know exactly but she was little bit concerned that the POT documented may shorten Mary's life or that we were doing this too soon. Laura told Hanna that it was right thing to do for Mary but it was hard for her to take. Hanna tried to comfort Laura by saying that this process was to help Laura reconcile where she was going. It could be 6 weeks or could be more likely to be a year but we did not have a time-frame on these things. It meant that Laura and Milson were having a think about Mary's illness and the impact of it, if Mary got sick what we wanted to achieve, what we wanted for her. It was about what we wanted for her in her lifetime if Mary could not tell us what she wanted. People wanted to have a good life, meaningful life. They wanted to have a say in their own decision which we called it autonomy. If they could not do that then we had to roll on to do beneficence to do good things to people. We wanted to maximise opportunity to enjoy things, like the food she eats, the music she listens, the sensory things she takes in. But we wanted to avoid the life that Mary may not appreciate and to minimise unnecessary suffering and pain. So that was what we are trying to do for her, trying to give her the opportunities and to keep the balance.</p>	<ul style="list-style-type: none"> <li>• Observing,</li> <li>• Measuring,</li> <li>• Assessing of any changes in pathological, physiological, psychological, functional, spiritual aspects</li> <li>• Enabling,</li> <li>• Empowering to make decisions,</li> <li>• Processing clinical judgement,</li> <li>• Discussing,</li> <li>• Counselling</li> </ul> <ul style="list-style-type: none"> <li>• Observing,</li> <li>• Measuring, &amp;</li> <li>• Assessing of any changes in pathological, physiological, psychological, functional, spiritual aspects</li> <li>• Supporting the family,</li> <li>• Enabling, &amp;</li> <li>• Empowering to make decisions,</li> <li>• Processing clinical judgement,</li> <li>• Discussing,</li> <li>• Counselling,</li> </ul>		
---	---	--	--



<p>Hanna went on to say that a lot of people think that this was about talking it through and then having a bit of a think. Hanna got a number of calls from people who wanted to talk about advance care planning when she gave a talk to the people with dementia and their carers in the community. So it was sort of talking about all the sorts of things that we did not ever ask questions about in advance because life was going to jinx people by asking. We were trying to change that culture by saying that let us have a think about what we were doing, where we were going, what we were trying to achieve. It was a peaceful uncomplicated death where no one suffered. However, we did not deny people treatment. We looked at what was going to achieve if we provided it and if it would be a good thing. Hanna added that in her experience she had not met many 80s and 90s who were saying 'give them everything at all cost just keep them going'. Laura said that we were guided by Mary's faith. They would not want unnecessary extension of life at all costs. They knew that Mary would not want tubes or a mask so that has been a part in her decisions. Considering the type of person she (Mary) was, she would like to be in control of her faculties. Hopefully they had made decisions that were consistent with her wishes.</p> <p>Milson and Laura were given two weeks to think about what has been discussed today. Hanna would come back in two weeks to answer their questions and to address their concerns, if any.</p> <p><u>During the third visit</u>, Hanna brought the POT form to be signed by Milson and Laura. Hanna read out what had been discussed and written. She asked Milson and Laura how they felt about doing the POT for Mary. They said that it was not easy to understand and accept in the beginning. Laura said that it was a hard thing to do because they went through the book and found all the different levels of care were too much to take. They realised that they would need professional help to understand the idea and apply it to Mary's case. By having Hanna who provided all the help and support they understood and agreed that they made decisions based on who Mary was, how she lived her life, and what she would have done if she was able to speak for herself. Hanna ensured Milson and Laura that the POT would not hasten or shorten Mary's death but would promote her comfort and well-being. Milson and Laura agreed with all and they both signed. They were informed that they could change or revoke the POT. Hanna informed them that POT would be reviewed in six months, following an 'event', or anytime they wanted to.</p> <p>Milson asked Hanna to pass the POT to the nursing-home staff. Hanna told Milson</p>	<ul style="list-style-type: none"> <li>• Discussing,</li> <li>• Supporting the family,</li> <li>• Enabling, &amp;</li> <li>• Empowering to make decisions,</li> <li>• Processing clinical judgement,</li> <li>• Counselling.</li> </ul> <ul style="list-style-type: none"> <li>• Supporting the family,</li> <li>• Developing, &amp;</li> <li>• Planning POT.</li> </ul> <ul style="list-style-type: none"> <li>• Supporting the family,</li> <li>• Developing, &amp;</li> <li>• Planning POT,</li> <li>• Enabling, &amp;</li> <li>• Empowering to make decisions,</li> <li>• Promoting knowledge.</li> </ul> <ul style="list-style-type: none"> <li>• Conveying,</li> <li>• Recording,</li> </ul>	<ul style="list-style-type: none"> <li>• Conveying,</li> <li>• Recording,</li> </ul>	<ul style="list-style-type: none"> <li>• Conveying,</li> <li>• Recording,</li> </ul>
--	---	--	--

<p>and Laura that the nursing home staff and Dr Thompson would be informed about the discussion and the decisions made. Hanna came back to the facility and informed the DON and the staff on duty about Mary's completed POT. Hanna made a photocopy of the POT and sent it to Dr. Thompson. The DON made a photocopy of the POT and placed it in Mary's file. She also made a note in the RNs' communication book that Mary now had documented a POT and where it could be found. The information was handed over to the afternoon shift. The DON rang Milson and Laura to see how they were doing. Milson and Laura were advised that the POT documented was in place, and were assured that the wishes made would be respected. The DON made herself available to Milson and Laura if they needed any help.</p> <p>The RNs provided Mary with the care she was receiving before the documentation of POT. Mary's ADL were well maintained and all the medications administered as prescribed by Dr Thompson as long as Mary would take them. The RNs organised the Physiotherapist in the facility to reassess Mary's mobility. The staff would observe her closely if she developed any acute illness.</p>	<ul style="list-style-type: none"> <li>• Reporting messages in relation to POT.</li> </ul>	<ul style="list-style-type: none"> <li>• Reporting messages in relation to POT,</li> <li>• Counselling,</li> <li>• Supporting of the family.</li> </ul>	<ul style="list-style-type: none"> <li>• Reporting messages in relation to POT.</li> <li>• Observing,</li> <li>• Measuring, &amp;</li> <li>• Assessing of any changes in pathological, physiological, psychological, functional, spiritual aspects</li> <li>• Maintaining current functions,</li> <li>• Providing therapeutic agents,</li> <li>• Enhancing comfort.</li> </ul>
---	--	---	--

<b>Exemplum 3: The story of Mic</b>	<b>CNC</b>	<b>Managers</b>	<b>RNs</b>
<p>Mic's story was chosen to juxtapose the best and limited practice by nurses involved in the ACP process and its outcomes.</p> <p>Mic was an Italian man who never married. He was only in his early 70s. His brother died of cancer 2 years ago and his sister-in-law was only his close family member. Mic was under the care of a Public Guardian, Ben, as his sister-in-law refused to be involved in Mic's care and finance. Mic had end-stage renal failure, AF, IHD, HT, dementia, colostomy bag (due to colon cancer) and a necrotic pressure sore on his left heel which he developed during previous hospitalisation. His MMSE was 17/30</p>			



<p>only minimal. He would open his eyes if his name was called but then closed his eyes. He would only take a couple of spoons of custard and cups of juice or tea per day.</p> <p>RN Donna set up a table and chairs for a Guardianship Tribunal Hearing for Mic at 9.30a.m. on 13/07/06. Mic was in a water chair and was asleep. Mario (interpreter), Marshala (from the Office of Public Guardian), Kara (independent person to support Mic), Maria (AIN), and Donna (RN) attended the hearing. Kara was appointed by the Guardianship Board to represent Mic independently so Mic could be given a fair chance. The hearing was to find out if he could express himself and what he would want. Mic was sleeping and they couldn't wake him up.</p> <p>If Frank or the family didn't agree with this Guardianship Tribunal decision then the next step was to go to an 'Administrative Decision Hearing', then 'Supreme Court'. Marshala and Donna thought that Mic would die before the problem would be resolved if they had to go all the way to the Supreme Court. Donna was frustrated because she didn't know who was responsible for the comfort and dignity of Mic during this process and who was responsible for his suffering during that time.</p> <p>Marshala told that when he was capable of expressing himself he wanted to have dialysis and that was just 5 months ago. He thought he would get better if he had dialysis but he didn't comply with the treatment, as he turned up to the dialysis unit with 9 litres of fluid instead of 3 litres. She thought he may realised that he didn't get any better so decided to die and became non-compliant.</p> <p>The interpreter and Maria kept talking to Mic to wake him up and he did. He slept for about 30 – 40 mins. So the hearing began. Kara told Mario to ask Mic "how are you?" There was no response. Mic just looked at the interpreter then he looked at the ceiling. He coughed a bit. Mic was asked "Have you got a cough?", again there was no response from him. Marshala said to him "people are concerned about you". Again no response from Mic. He just looked at the air, ceiling ... Then showed us a black expression. They asked a couple more questions but Mic didn't respond at all.</p> <p>Kara and Marshala decided that there was no point in asking more questions. Marshala asked Mic if there was anything that he would like to tell us. No response. So they decided to wrap up. Mic was taken out of the room and the interpreter left. The hearing lasted for one hour.</p> <p>Kara told me that she was in shock to see how quickly Mic had deteriorated since</p>			<ul style="list-style-type: none"> <li>• Advocating,</li> </ul>
---	--	--	---

<p>May. He was able to talk to her and even correct someone's Italian pronunciation. She said it was an extremely quick deterioration. Marshala said that Kara would consult a psychogeriatrician to assess Mic. Then when they had all the information there would be a discussion with the family and everyone who was concerned about Mic. But Marshala said again that Mic would die before it was resolved.</p> <p>Nothing much has happened since the last Guardianship hearing. He was sent to the hospital for dialysis 3 times a week. Mic was less and less responsive or interactive. RN Chris found that Mic's case was referred to 'Administrative Decision Making' as his friend or business partner Frank would not accept Mic's condition and kept insisting on futile dialysis against Mic's wish. Mic's sister-in-law said that it was an evil thing to do to keep him alive like this. She said his friend must be evil to do this to Mic as she thought Mic was suffering from pain and discomfort by his life being prolonged this way. RN Chris was also frustrated about why they couldn't let him die in comfort and pain-free. She said that it was not right, not the right thing to do.</p> <p>Mic was sent to the hospital on Friday 04/08/06. He was chesty and had been coughing. His BT was 37.4. Mic's case was now referred to the Supreme Court but there was no report of progress in the procedure. Nursing home staff found that Mic died in the hospital on 13/08/06.</p>			
---	--	--	--

<b>Exemplum 4: The story of Vic</b>	<b>CNC</b>	<b>Managers</b>	<b>RNs</b>
<p>Vic's story was chosen to juxtapose the best and limited practice by nurses involved in the ACP process and its outcomes.</p> <p>Vic was admitted to Amen nursing home on 13/04/06. His wife and he immigrated from Egypt to Australia 36 years ago. His wife died of breast cancer 7 years ago. They had no children. Vic was cognitively alert but couldn't talk, as he had MND. He wrote clearly though, what he wanted. Tanya was Vic's POA. Tanya and Vic's best mate Jax visited him 2 or 3 times a week. Vic had expressed his wishes to Dr Phill not to transfer to hospital and not to resuscitate him. In his chart it was clearly stated 'no transfer to hospital or resuscitation'. He made this wish when Dr Phill came in to admit him. Dr Phill talked to RN Donna that Vic wanted to die here so it would be necessary to contact his brother in Brazil or appoint a guardian. Dr Phill said that Vic's MND has weakened his respiratory system and Vic required 24-hr oxygen. Dr Phill asked Vic that if he would</p>			

<p>like them to contact his brother in Brazil. Vic waved his hand meaning 'NO'. He was definite that he didn't want to contact his brother in Brazil re his relocation in the nursing home and his wishes not to be hospitalised. Donna told Dr Phill that Tanya was his POA so he didn't have to contact his brother and they could document something with Tanya. It was noted that Dr Phill and Donna didn't know the difference between POA and EG.</p> <p>Vic enjoyed chatting with Tim (AIN) although he was not able to talk. Vic wrote on the note pad what he wanted to say and Tim would talk to him. Tim asked Vic why he didn't want to be transferred to hospital. He wrote it was a very bad place. Tim asked him what about. Vic gestured everything. Vic wrote 'everything, the staff, the food. Vic also told Tim 'no CPR' because, Vic frowned his face and pointed his legs and pointed his arms in the air meaning 'nothing to look forward to! Vic wrote everything was wrong and sad. He said that there was nothing to look forward to and he had enough. Tim asked Vic if he had a nice experience in the nursing home and the staff here looked after him well, then he might change his mind. He said maybe.</p> <p>Tim was allocated to look after Vic 2 weeks later. Tim asked Vic if he changed his mind since he told not to transfer him to hospital. He said no, meaning his mind was the same. He didn't want to be transferred to hospital. He said he would like to buy a gun and shoot himself on his head and asked Tim to help him. Tim told him that guns were expensive and he didn't know where to get it. Vic said it's \$300 and he knew where to get one. Tim told Vic that he should lock Vic up here in the nursing home then. They laughed. Vic stated a couple of times that he wanted to shoot himself in the head if he had a gun. Tim told the RN Sonya who was a casual nurse what Vic had told him. Sonya took it as a joke, saying that she wanted to borrow the gun to rob a bank. Tim told him that he might change his mind if he settled in the nursing home and if he made friends and participated in recreation therapy. He made a gesture meaning that may be so.</p> <p>No RN seemed to notice and addressed his wishes for a number of weeks. There was no call for a conference with his close friends about his wishes. Nothing was organised with regard to what he mentioned.</p> <p>He had experienced SOB and his condition seemed to be deteriorating. But there was no significant change in his treatment plan other than daily fluid restriction due to CCF, as there was nothing they could do. His legs were very swollen and all his toes were in purple colour. Pitting oedema was extensive. In his note, he had scrotum oedema too.</p>			
---	--	--	--

<p>Tanya said she believed in euthanasia. She wouldn't have wanted to live like him. She said she knew Vic had asked Dr Phill not to send him to hospital or not to resuscitate him. She thought he may be confused and he was strange occasionally. She said he threatened people while he was in the hospital that he would slash his wrist but in other times he wanted to eat and enjoyed the food. So Tanya was not sure what to do. She said she would send him to hospital if he got sicker than this. She said she would have to. She said she had the legal power to make decisions for him not only in financial matters but also medical decisions as well.</p> <p>Vic was found dead by RN Agnes in bed at 13.30 p.m. on 23/06/06.</p>			
--	--	--	--