“Behind the Blue Door”: developing the practices of aged care staff around a palliative approach in a dementia special care unit

by

Sharon M. Andrews, RN, BN (Hons)

Submitted in fulfilment of the requirements

for the degree of

Doctor of Philosophy

University of Tasmania

November, 2010
Declaration

Statement of Original Authorship

I hereby declare that this thesis is my own work and contains no material which has been accepted for a degree or diploma by the University of Tasmania or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

Name: Sharon Mary Andrews

Signed:

Date:

Statement of Authority

This thesis may be made available for loan and limited copying in accordance with the “Copyright Act 1968”.

Name: Sharon Mary Andrews

Signed:

Date:

Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

Name: Sharon Mary Andrews

Signed:

Date:
Abstract

The adoption of a palliative approach to the care within Australian Residential Aged Care Facilities (RACFs) has been supported by a range of policy and best-practice initiatives. There is a considerable body of evidence demonstrating that most people who live in RACFs are highly dependent, are likely to have dementia and will die in these locations. Dementia is recognised to be a terminal condition, further underscoring the need for appropriate and timely care. However, issues of equity and quality of palliative care for people with dementia have raised concerns about the capacity of RACFs to deliver a palliative approach to care. Therefore, this research located within a RACF in Tasmania, Australia, sought to address the question: *what are the possibilities for aged care staff to develop their practices around a palliative approach to care for people with dementia and their family caregivers?*

The study employed a critical action research method wherein, nursing and care staff members (n=5) from a dementia special care unit (SCU) formed an action research group (ARG). With a desire to explore and improve their palliative care practices, the ARG members engaged in a critical change agenda over an 18 month period. In Stage One of the study, a preliminary investigation collected baseline from ARG meetings (n=11), staff questionnaires (n=37), interviews with family caregivers of residents from the SCU (n=10), stakeholders dialogues (n=6); and an audit of resident files (n=21). Through their critical reflection on the baseline findings, the ARG members identified three areas of practice in need of improvement these being, i) staff knowledge of a palliative approach, (ii) family caregivers’ access to information and, (iii) evidence-based strategies for pain management and palliative care planning. During Stage Two, the ARG members continued to meet (n=7) as co-researchers and developed four action plans to address these concerns. During this process they shared an emerging sense of empowerment as they imagined possibilities for change. In Stage Three, the group members implemented their action plans through five successive action cycles and met (n=9) to critically reflect on the outcomes. This study illustrates that a complexity of competing economic, socio-political and cultural interests shape the possibilities for aged care staff to reconfigure their practices to support a palliative approach to care. It is imperative to provide opportunities for staff to engage in critical, collaborative dialogue as a means to exposing the taken-for-granted understandings that constrain innovation.
Acknowledgments

This thesis would not have been possible without the support, guidance and care of many generous people. I would like to sincerely thank these people.

Firstly, to my supervisors thank you for your generosity at every point. I owe a debt of gratitude to my primary supervisor Andrew Robinson from whom I have learnt many skills that I will carry with me throughout my career. Your trust in my ability, your unyielding critique and an authentic desire for me to do the best that I could, helped me do more than what I had envisaged. Oh, and Andrew …I get it… “it’s all about telling the story!”.

Thank you to Camillus Parkinson, my co-supervisor who has been a long-term mentor and friend, I hope that in the future I can be as kind and patient as you have been during my journey. Thanks to Chris Toye, my co-supervisor who was always so generous with her time and expertise. Your attention to detail and encouragement helped me get there. I am also eternally grateful to Fran McInerney, who joined my supervision team later in the journey. Your support and honest (at times confronting) feedback was crucial in helping me realise the full potential of this story and I feel privileged to have had your assistance.

With great appreciation I acknowledge Southern Cross Care (Tas) Inc. for their kind contribution to funding my PhD scholarship in partnership with the University of Tasmania. In particular, I am especially grateful for the support of Carolyn Wallace who, over the past five years has helped me to better understand the ins and outs of aged care.

Thank you to the staff members of the action research group who so willingly shared with me their experiences and their aspirations. This project would not have been possible without your participation and dedication to “make things better”. I feel privileged to have worked with you all. I am also very grateful to those family caregivers, other SCU staff and GPs who contributed to the project. Sharing stories is not always easy.

Benjamin, we finally got there (and no more proof reading!). I am filled with admiration for the patience, love and steadfast support that you have provided so willingly – from my heart, thank you.

To my sister, Michele… you know the effort and sacrifice this has taken. Thank you for being with me and understanding. Mum and Dad, I have been able to undertake this work because of your sacrifices – thank you. Irene and David, many thanks for your belief in me, support for me through this journey and the many glasses of wine. Sue, you have been a constant companion and source of sanity (and ‘Sex and the City’) on this long and at times arduous journey.

Kathleen, you have become a great friend. Thank you for listening to my concerns doubts and for the stark raving crazy moments. I owe you dinner and a good bottle of bubbles – probably two bottles. Last but by no means least, Will, Carolanne (and Bumpy) thank you for being part of this experience – you are very special people and …I’m done, I’m done, I’m done… “It’s not difficult to say!”
I dedicate this thesis to Arthur Fitzroy-Ezzy (‘Grandad’).
Contents

Declaration ......................................................................................... ii
Abstract ............................................................................................ iii
Acknowledgments ............................................................................ iv
Contents ............................................................................................ vi
List of tables ..................................................................................... x
List of figures .................................................................................... xi
Glossary of key terms ......................................................................... xii
Abbreviations ................................................................................... xiv
Papers arising from this research ...................................................... xv

Chapter 1: Introduction .......................................................................... 1

1.1 Setting the scene ........................................................................... 1

1.2 Research problem and rationale ....................................................... 3
  1.2.1 Attempts to integrate palliative care into the aged care sector .... 4
  1.2.2 Problems with the translation of evidence into practice .......... 5

1.3 Methodological approach ................................................................ 6

1.4 Structure of the thesis .................................................................... 8

Chapter 2: Literature Review ................................................................. 11

2.1 Background ................................................................................... 11
  2.1.1 Population ageing and implications ....................................... 12
  2.1.2 The changing face of residential aged care: emergence of economic rationalism ... 14

2.2 The dementia trajectory and implications for care provision in RACFs .... 17
  2.2.1 Dementia: a terminal condition ............................................. 17
  2.2.2 Characteristics of the dementia trajectory ................................ 18
  2.2.3 Recognition of dementia as a terminal condition ................... 19
  2.2.4 Socio-cultural considerations: dying, death and dementia ...... 20

2.3 Expanded applicability of palliative care .......................................... 22
  2.3.1 Evolution of palliative care .................................................. 22
  2.3.2 The spectrum of palliative care ............................................ 24
  2.3.3 Issues in the provision of palliative care for people with dementia .... 26

2.4 Developments supporting a palliative approach in RACFs ................. 31

2.5 Translation of evidence into practice in RACFs: competing tensions .... 33
  2.5.1 Experience and expertise of RACF staff in evidence-based practice ... 34
  2.5.2 Contextual factors influencing evidence-based practice in the RAC setting .... 35

2.6 A way forward ............................................................................... 43

Chapter 3: Theoretical and Methodological Foundations ....................... 45

3.1 Critical theory – an introduction .................................................... 45

3.2 Concepts central to critical theory ................................................... 47
  3.2.1 Hegemony, ideology and taken-for-granted understandings .......... 47

3.3 The relevance of knowledge-constitutive interests .......................... 50

3.4 The centrality of language and communication in exposing hegemony .... 52
  3.4.1 Communicative competence .................................................. 52
  3.4.2 Communicative action .......................................................... 54
5.4 Palliative care in the aged care environment ................................................. 114
  5.4.1 Preparedness of staff to talk about death and dying ................................ 117
  5.4.2 Awareness of the Palliative Approach Guidelines ...................................... 118

5.5 Discussion ........................................................................................................ 119

Chapter 6: Action Cycle 1 - Scoping the Issues ....................................................... 126

6.1 Sub-cycle 1: staff surveys ............................................................................... 128
  6.1.1 Plan ........................................................................................................... 129
  6.1.2 Take action and collect data ...................................................................... 130
  6.1.3 First level analysis: researcher facilitated ............................................... 130
  6.1.4 Reflection of ARG members: collaborative analysis of the data ............. 140

6.2 Sub-cycle 2: resident documentation audit .................................................... 143
  6.2.1 Plan ........................................................................................................... 144
  6.2.2 Take action and collect data ...................................................................... 144
  6.2.3 First level analysis: researcher facilitated ............................................... 144
  6.2.4 Reflection of ARG members: collaborative analysis of the data ............. 153

6.3 Sub-cycle 3: family caregiver interviews ....................................................... 156
  6.3.1 Plan ........................................................................................................... 156
  6.3.2 Take action and collect data ...................................................................... 157
  6.3.3 Analysis and evaluation .......................................................................... 158
  6.4.4 Reflection of ARG members: collaborative analysis of the data ............. 166

6.4 Sub-cycle 4: critical dialogues with key staff ................................................ 169
  6.4.1 Plan: ........................................................................................................... 169
  6.4.2 Take action and collect data ...................................................................... 170
  6.4.3 First level analysis .................................................................................... 171
  6.4.4 Reflection of ARG members: collaborative analysis of the data ............. 176

6.5 Discussion ........................................................................................................ 178

Stage 2: Emerging Empowerment ....................................................................... 190

Chapter 7: Developing comprehensive intervention strategies ......................... 191

7.1 Action cycle 2 ................................................................................................ 191
  7.1.1 Plan ........................................................................................................... 191
  7.1.2 Take action and collect data ...................................................................... 193
  7.1.3 Knowledge and information needs of key stakeholders .......................... 193
  7.1.4 Reconfiguring care practices .................................................................... 198
  7.1.5 Analysis and reflection ............................................................................. 203

7.2 Action cycle 3: Feedback to key stakeholders ................................................ 204
  7.2.1 Plan ........................................................................................................... 205
  7.2.2 Take action and collect data ...................................................................... 205
  7.2.3 Analysis and reflection ............................................................................. 208

7.3 Discussion ........................................................................................................ 209

Stage 3: Reconfiguring Practices: Engaging in The Politics of Change ............... 212

Chapter 8: Taking action to support evidence-based practice: part I ................. 213

8.1 Action cycle 4: staff education sessions ....................................................... 213
  8.1.1 Planning action ........................................................................................ 214
  8.1.2 Take action and collect data ...................................................................... 215
  8.1.3 Analysis and reflection ............................................................................. 217

8.2 Action cycle 5: addressing information needs of family caregivers .............. 222
  8.2.1 Take action and collect data ...................................................................... 223
  8.2.2 Analysis of data and reflection .................................................................. 225

8.3 Post-script: measures for sustainability ......................................................... 232
List of tables

Table 1  Framework for monitoring change ................................................. 71
Table 2  Profile of staff at RACF (N=160) .................................................... 78
Table 3  Staffing profile for SCU per shift, equivalent full-time ......................... 78
Table 4  Demographic data for ARG members .............................................. 82
Table 5  Number of ARG meetings, each stage of the project .............................. 87
Table 6  Questionnaire respondents (n=37) ................................................. 131
Table 7  Previous education about palliative care ......................................... 132
Table 8  Type of palliative care education attended (formal and informal) ............ 132
Table 9  Previous education about dementia .................................................. 133
Table 10 Type of dementia education attended (formal and informal) ................. 133
Table 11 Responses to item 6 on the PAQ .................................................... 135
Table 12 Responses to item 9 on the PAQ .................................................... 136
Table 13 Responses to item 10 on the PAQ ................................................... 136
Table 14 Responses to item 13 on the PAQ ................................................... 137
Table 15 Responses item 1 of KDQ ............................................................. 140
Table 16 Responses item 9 of KDQ ............................................................. 140
Table 17 Result of resident documentation audit for domains 1 to 5 (n=15) ......... 146
Table 18 Result of resident documentation audit for domains 6 to 8 (n=6) ............ 151
Table 19 Interview participants, relationship to the resident and resident length of stay in the SCU at the time of interview ...................................................... 157
Table 20 Critical dialogue participants .......................................................... 170
Table 20 Staff responses to items on education session feedback form (n=12) ....... 218
Table 21 Family caregivers responses: evaluation of information booklet (n=21) 226
Table 22 Family caregivers responses: evaluation of fact sheet (n=21) ................. 226
# List of figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>The action research process</td>
<td>8</td>
</tr>
<tr>
<td>Figure 2</td>
<td>Action Cycle 1</td>
<td>128</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Action Plan 1</td>
<td>129</td>
</tr>
<tr>
<td>Figure 4</td>
<td>Action Plan 1 – Staff surveys</td>
<td>129</td>
</tr>
<tr>
<td>Figure 5</td>
<td>Percentage of total correct responses for PAQ</td>
<td>135</td>
</tr>
<tr>
<td>Figure 6</td>
<td>Percentage of total correct responses for KDQ</td>
<td>138</td>
</tr>
<tr>
<td>Figure 7</td>
<td>Percentage of total correct responses, treatment and care sub-scale</td>
<td>138</td>
</tr>
<tr>
<td>Figure 8</td>
<td>Percentage of total correct responses, signs and symptoms sub-scale</td>
<td>139</td>
</tr>
<tr>
<td>Figure 9</td>
<td>Action Plan 2</td>
<td>143</td>
</tr>
<tr>
<td>Figure 10</td>
<td>Action Plan 2 – Documentation audit</td>
<td>144</td>
</tr>
<tr>
<td>Figure 11</td>
<td>Action Plan 3</td>
<td>156</td>
</tr>
<tr>
<td>Figure 12</td>
<td>Action Plan 3 – Family caregiver interviews</td>
<td>156</td>
</tr>
<tr>
<td>Figure 13</td>
<td>Action Plan 4</td>
<td>169</td>
</tr>
<tr>
<td>Figure 14</td>
<td>Action plan 4 – Critical dialogues with key staff</td>
<td>169</td>
</tr>
<tr>
<td>Figure 15</td>
<td>Action Cycle 2</td>
<td>192</td>
</tr>
<tr>
<td>Figure 16</td>
<td>Action Cycle 3</td>
<td>204</td>
</tr>
<tr>
<td>Figure 17</td>
<td>Action cycle 3 - Action plan</td>
<td>205</td>
</tr>
<tr>
<td>Figure 18</td>
<td>Action Cycle 4</td>
<td>213</td>
</tr>
<tr>
<td>Figure 19</td>
<td>Action Cycle 4 - Action plan</td>
<td>214</td>
</tr>
<tr>
<td>Figure 20</td>
<td>Action Cycle 5: Addressing information needs of family caregivers</td>
<td>222</td>
</tr>
<tr>
<td>Figure 21</td>
<td>Action Cycle 5 - Action plan</td>
<td>223</td>
</tr>
<tr>
<td>Figure 22</td>
<td>Action Cycles 6-8</td>
<td>240</td>
</tr>
<tr>
<td>Figure 23</td>
<td>Action Cycle 6</td>
<td>240</td>
</tr>
<tr>
<td>Figure 24</td>
<td>Action Cycle 6 - Action plan</td>
<td>242</td>
</tr>
<tr>
<td>Figure 25</td>
<td>Pilot of PAM form for one resident</td>
<td>244</td>
</tr>
<tr>
<td>Figure 26</td>
<td>Action Cycle 7</td>
<td>250</td>
</tr>
<tr>
<td>Figure 27</td>
<td>Action Cycle 7 - Action plan</td>
<td>251</td>
</tr>
<tr>
<td>Figure 28</td>
<td>Action Cycle 8</td>
<td>255</td>
</tr>
<tr>
<td>Figure 29</td>
<td>Action Cycle 8 - Action plan</td>
<td>258</td>
</tr>
</tbody>
</table>
Aged Care Standards and Accreditation Agency: “The accreditation body for the purposes of the Aged Care Act 1997 (section 99-3(5)).” Core functions of the agency are to: manage the residential care accreditation process using the Accreditation Standards; promote high quality care and assist the industry to improve services quality; assess and manage services working towards accreditation; liaise with the department of Health and Ageing about services that do not comply with the relevant regulatory Standards (Hogan 2004, p.240).

Allied Health Professional and Workers: These professionals include occupational therapists, dentists, physiotherapists, podiatrists and contribute to the care of residents but are not recognised as part of the dedicated aged care workforce. Allied health workers may include diversional therapists and recreational officers (Access Economics 2009b, p.4).

Enrolled Nurse: A nurse who is enrolled with the relevant nursing and midwifery board of the state or territory in Australia. The minimum requirement for education of an enrolled Nurse is a one-year diploma from a Vocational Education and Training Provider (VET), e.g., TAFE, Certificate level IV. Enrolled Nurses under the supervision of Registered Nurses to provide basic nursing care and undertake less complex tasks of medication management and client monitoring (Access Economics 2009b, p.4).

Registered Nurse: A nurse who is registered by the relevant nursing and midwifery board of the state or territory in Australia. The minimum requirement for education for a Registered Nurse is a three-year degree from a higher education institution or equivalent recognised hospitals based program. In some stated they are referred to as a Division 1 Nurse. They manage teams of care staff in aged care facilities; provide specialist care
skills and complex medication and care tasks (Access Economics 2009b, p.4).

Personal Care Assistants: These are unregulated workers who undergo training in the VET Sector to Certificate Level III. They are supervised workers and undertake routine tasks in the provision of services to assist clients with activities of daily living (Access Economics 2009b, p.4).

PRN (‘Pro re nata’): This word translates from Latin to the English language as ‘the need arises’ and is commonly referred to in abbreviate from as ‘PRN’ (Dirckx 1983, p.50). A PRN medication is a medication that is administered ‘when required’.

Residential Aged Care: refers to care provided to older people, where the care is:

1. “... personal care or nursing care, or both personal care and nursing care, that:
   a. is provided to a person in a residential facility in which the person is also provided with accommodation that includes:
      i. appropriate staffing to meet the nursing and personal care needs of the person; and
      ii. meals and cleaning services; and
      iii. furnishings, furniture and equipment for the provision of that care and accommodation” (The Aged Care Act 1997, section.41-4).

Residential Aged Care Facility: refers to the organisation providing residential aged care (These are still commonly referred to as ‘nursing homes’ and ‘hostels’. The latter term is used when referring to earlier legislation and residential aged care homes in the USA and the UK).

Incidental Pain: Pain that occurs no or is exacerbated by activity (Therapeutic Guidelines, 2005, p. 174).
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP</td>
<td>Advance care planning</td>
</tr>
<tr>
<td>ADON</td>
<td>Assistant Director of Nursing</td>
</tr>
<tr>
<td>AH</td>
<td>Allied health (assistants or staff member)</td>
</tr>
<tr>
<td>ARG</td>
<td>Action Research Group</td>
</tr>
<tr>
<td>APRAC</td>
<td>Australian Palliative Residential Aged Care</td>
</tr>
<tr>
<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
</tr>
<tr>
<td>ECA</td>
<td>Extended Care Assistant</td>
</tr>
<tr>
<td>EN</td>
<td>Enrolled Nurse</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HLA</td>
<td>Health and Life Assessment</td>
</tr>
<tr>
<td>KDQ</td>
<td>Knowledge of Dementia Quiz</td>
</tr>
<tr>
<td>LPNs</td>
<td>Licensed Practical Nurses (US)</td>
</tr>
<tr>
<td>NCHSPCS</td>
<td>National Council for Hospice and Specialist Palliative Care</td>
</tr>
<tr>
<td>PAM</td>
<td>Pain Assessment and Management</td>
</tr>
<tr>
<td>PAQ</td>
<td>Palliative Approach Quiz</td>
</tr>
<tr>
<td>PCAs</td>
<td>Personal Care Assistants</td>
</tr>
<tr>
<td>POT</td>
<td>Plan of Treatment</td>
</tr>
<tr>
<td>RAC</td>
<td>Residential Aged Care</td>
</tr>
<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
</tr>
<tr>
<td>RCS</td>
<td>Resident Classification Scale</td>
</tr>
<tr>
<td>RN</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>RPCP</td>
<td>Respecting Patient Choices Program</td>
</tr>
<tr>
<td>SCU</td>
<td>special care unit</td>
</tr>
<tr>
<td>SDAC</td>
<td>Survey of Disability Ageing and Carers</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
Papers arising from this research


Andrews, S, 2010, ‘Behind the blue door: developing the practices of aged care staff around an evidence based palliative approach to care’, Plenary paper, Wicking Dementia Research and Education Centre Summer School, Progressing the Translation of Dementia Research into Practice, 3rd – 5th February, Medical Science 1 building, Hobart.


Chapter 1: Introduction

1.1 Setting the scene

With a new case of dementia in the world every seven seconds there is no time to lose (Acosta & Wortmann 2009, p. 2).

At the beginning of the 21st century a position paper prepared for Alzheimer’s Australia by Jorm (2001, p. 1) argued that dementia was “one of the biggest health problems facing Australia right now and it will be an even bigger one in the future”. In 2003, a report by Access Economics entitled ‘The Dementia Epidemic: Economic Impact and Positive Solutions for Australia’, was one of the landmark publications in Australia that raised awareness about the future impact of dementia in terms of projected prevalence, associated disability and economic implications (Access Economics 2003). Subsequently, in early 2005, at the beginning of this study, Australia became the first country in the world to make dementia a national health priority. The impacts of rising prevalence and incidence of dementia on the Australian health care system and society as a whole were recognised as issues of national significance resulting in the release of the “The National Framework for Action on Dementia 2006-2010” (Australian Health Ministers’ Conference 2006). Other countries, such as the UK, France and South Korea have since followed suit and developed national dementia plans (Alzheimer's Disease International 2009).

The importance of nationally co-ordinated action plans to cope with the impact of dementia around the world is underscored by international data, estimating that there are 35.6 million people with dementia worldwide (Alzheimer's Disease International 2009). By 2030 this figure will double to 65.7 million and in 2050 it is predicted that there will be 115.4 million people with dementia. Since the inception of this study there has been an explosion of dementia-related interest, activity and research across governments, policy makers, health care sectors, providers, professionals, interest groups and consumers. In a recent address at The National Press Club, in Canberra, Professor Constantine Lyketsos (2009) implored researchers and governments alike to continue to invest in ongoing knowledge development and translation across the
spectrum of dementia diagnosis, early intervention, treatment and care. He provides a compelling case in his following statement:

 Governments in the last century tackled polio, cancer, heart disease and HIV/AIDS with passion and commitment. My message is simple. We need the same passion and commitment to resolve the enormous challenges that dementia poses for our health care systems and for our society. Let’s be clear. The dementia epidemic is upon us (p.4).

While this study is positioned within a plethora of literature and policies spanning local, national and international concerns around services and support for people with dementia and their family caregivers, it is important to acknowledge that the impetus for the research developed out of local concerns within a Residential Aged Care Facility (RACF) in Tasmania, Australia. Having worked intermittently in this facility three years prior to the beginning of this study, and having had previous experiences working in a specialist palliative care service, I had developed a considerable interest in and desire to improve the delivery of palliative care for people with dementia. Over this time, I had recognised obvious disparities in the care that I and other staff members could provide in the RACF compared to the inpatient specialist palliative care setting. Yet, the needs of people with dementia in the RACF appeared to me in many ways comparable to the needs of people, usually with cancer, in the specialist setting. It was initially this dissonance and a sense of injustice that motivated my interest in improving the provision of palliative care for people with dementia.

As my interest around this concern grew, I realised that my colleagues in the facility shared similar concerns, but significantly, they felt a sense of powerlessness to improve the care that they provided to arguably the most vulnerable and dependent group of people in the facility. Moreover, the RACF was a hectic environment, where the bulk of nursing time was consumed with medication management and documentation and the majority of direct resident care tasks were undertaken by Personal Care Assistants (PCAs). Thus, the opportunities for nursing and care staff with whom I worked to discuss their concerns about the delivery of palliative care to people with dementia were few and far between. Serendipitously, as my interest around these issues grew I became aware of the release of the “Guidelines for a Palliative Approach in Residential Aged Care” (ADoHA 2004) (hereafter referred to as the Guidelines). These were evidence-based, best practice guidelines developed
through an extensive, systematic review of the literature that made recommendations to guide the provision of a palliative approach to care for people in RACFs. Therefore, from subtle beginnings, this study sought to answer the following question:

What are the possibilities for aged care staff to develop their practices around a palliative approach to care for people with dementia and their family caregivers?

It was from this question that I and a group of staff members from the dementia special care unit (SCU) at the facility embarked on a journey. This thesis chronicles that journey. Within this introductory chapter the research problem, aims and rationales will be outlined. The research approach chosen to inform and guide the study is then summarised and an overview of the thesis structure will be provided.

1.2 Research problem and rationale

...dementia does not seem to kill as quickly as cancer or heart disease.

But of course, dementia is terminal. (Lyketsos 2009, p. 5)

Research around caring for people with dementia in RACFs has expanded over the past two decades. In parallel, concerns about the quality of care provided for people with dementia and their family caregivers in this setting have also emerged. A particular area of concern underpinning this study relates to the provision of a palliative approach to care for these people. There is now compelling evidence that dementia is a terminal condition (Mitchell et al. 2009). However, the biological processes underlying dementia that inevitably leads to death is typically gradual and prolonged (Clark, 2000; Larson 2004; Warner & Butler 2000). Therefore, dementia is often not conceptualised as a terminal condition because of the often extended period of time between detection of the illness and death (Albinsson & Strang 2002; Sachs et al. 2004). Downs, Small and Froggatt (2006) suggest that the way that dementia is conceptualised shapes how those with this condition’s needs are understood and what possibilities are conceived for their care. The implications of dementia being under-recognised as a terminal illness by family caregivers (Chung 2000; Forbes, Bern-Klug & Gessert 2000; Gessert, Forbes & Bern-Klug 2001) and health professionals (Dharmasena & Forbes 2001; Hanrahan & Luchins 1995; Robinson et al. 2005b) has contributed to the less than optimal provision of palliative care for this vulnerable group of people. As such, Downs et al. (2006 p. 209) argue
that often “too little or too much care” is provided, both circumstances resulting in adverse effects for people with dementia and their family caregivers.

There is evidence to support the efficacy of a palliative approach to care for people with dementia (Ahronheim et al. 2000; Volicer et al. 1994; Volicer 2008). However, reviews of research and other literature (Robinson et al. 2005b; Birch & Draper 2008; Sachs et al. 2004) about the provision of palliation and end-of-life care for people with dementia have highlighted numerous deficits, with respect to quality of care and quality of life. As such, Robinson and colleagues (2005b p. 142) have argued that people dying with dementia represent the “disadvantaged dying”. People entering RACFs are older, frailer, more dependent (Andrews-Hall et al. 2007) and highly likely to have dementia (AIHW 2006b). The sub-optimal provision of palliative care in these settings has raised a range of economic, social and ethical arguments supporting the need to reconfigure care practices and broaden service provision (Froggatt et al. 2006; Abbey et al. 2006; Robinson et al. 2005b). In parallel, there has been increased advocacy for palliative care to be an international human right for people with life-limiting conditions (Brennan 2007), such as dementia.

Within the Australian aged care sector however, the capacity of staff to support a palliative approach to residents is questionable. Contextual factors such as a progressive deskilling of the aged care workforce (Chandler et al. 2005; Martin & King 2008), growing resident dependency (Andrews-Hall et al. 2007) in addition to increased administrative duties and regulatory requirements on nursing staff (Venturato et al. 2007) have culminated in a workforce largely overburdened and inadequately resourced to meet the complex needs of older people. Despite high workloads and staff rationalisation the demand for aged care staff to provide a high quality, evidence-based palliative approach to care is significant. Thus, attempts to more formally integrate palliative care within aged care practice have taken on greater emphasis over the past decade.

1.2.1 Attempts to integrate palliative care into the aged care sector

Since the late 1990s there has been significant work by Palliative Care Australia, the National palliative care peak body (PCA 2000), to establish frameworks that can contribute to positive discourses around dying and palliative care in Residential Aged Care (RAC) settings. These developments were reflected in Australian Government
policy (ADoHA 2000) and led to the publication of the earlier-noted Guidelines (ADoHA 2004) which have the potential to improve the provision of a palliative approach to care for people with dementia in RACFs. The Guidelines contain a dedicated section addressing issues about providing a palliative approach for people with advanced dementia, in addition to references to dementia integrated throughout the document. Extensive roll-out of the Guidelines’ content occurred across Australia in 2005, to raise awareness amongst aged care staff and to promote their implementation within the RAC sector (Currow & Hegarty 2006; Kristjanson 2005; PCA 2007). However, despite these activities, the extent to which RACFs have adopted and implemented the Guidelines remains unclear (Allen et al. 2008; Phillips et al. 2006).

Froggatt (2000b) and Abbey (2006) have argued that the integration of palliative care within RACFs requires careful attention to the specific cultural and contextual factors of these settings, suggesting that transferability is not as simple as replacing one set of practices with another. Similarly, in more recent research (Goodwin & Water 2009 p. 278) it has been argued that the provision of palliative care for people with dementia in RACFs is more “complex than could be met by the transfer of techniques” from the specialist palliative care or hospice settings. At the commencement of this study however, there was a dearth of evidence as to strategies for RACF staff to implement the Guidelines for people with dementia, within the highly complex and changeable environment of RAC. Yet literature suggests that contextual features (social, material and cultural) of RAC settings challenge the translation of evidence into practice (McConigley et al. 2008; Lyon 2007; Moore & Haralambous 2007; Phillips et al. 2006).

1.2.2 Problems with the translation of evidence into practice

Researchers have demonstrated the benefits of good dementia care, but knowledge translation to those delivering care has been all too slow. (Lyketsos 2009, p.5).

Recent Australian studies (Grbic et al. 2003; Phillips et al. 2006) within RAC settings have identified numerous deficits in palliative care provision for older people with non-malignant conditions. Additionally, the translation of palliative care evidence into practice with respect to the care of people with dementia in RACFs has been recognised as lacking (Robinson et al. 2005b; Birch & Draper 2008). It is
recognised that getting evidence into practice is a complex process (Rycroft-Malone et al. 2004; Kitson et al. 1998); an issue recently explicated with respect to the Australian RAC sector (Masso & McCarthy 2009). Masso and McCarthy (2009) have presented a synthesis of the literature highlighting how contextual factors of RAC settings pose ongoing challenges to translation.

As will be discussed in the following chapter, many factors impact on the implementation of evidence in the RAC setting, including that relevant to the palliative approach. Despite the growing understandings of contextual, organisational and professional barriers to the implementation of evidence-based practices (Rycroft-Malone et al. 2004), there remain gaps in the aged care literature as to how to facilitate the delivery of a palliative approach to care for people with dementia in RACFs (Phillips et al. 2008; Phillips et al. 2006). At the inception of this study, evidence about how RACF staff understood dementia and palliative care and operationalised palliative care in practice was limited (De Bellis & Parker 1998; Whittaker et al. 2007; Ersek et al. 2000; Clare & De Bellis 1997; Phillips et al. 2006). Critically, we still lack substantial insight into the organisational capacity of aged care providers to facilitate the delivery of an evidence-based palliative approach to care. Therefore, in seeking to address the research question, What are the possibilities for aged care staff to develop their practices around a palliative approach to care for people with dementia and their family caregivers, three sub-questions were developed:

- Is a palliative approach to care understood and reflected in the practices of aged care staff on the SCU and if so, how?
- What are the factors/conditions that constrain aged care staff in delivering an evidence-based palliative approach to care on the SCU?
- What strategies will enable/support aged care staff to develop their practices around an evidence-based palliative approach to care?

1.3 Methodological approach

Spilsbury and Meyer (2001 p. 10) have argued the need for more practitioner-centred methodologies to “unpack” the aspects of nursing work that are not readily accessible in traditional empirical research. Methods such as action research, that have an action orientation as well as a reflexive component, have been increasingly advocated by scholars in the field of ageing research (Spilsbury & Meyer 2001;
Meyer & Sturdy 2004; Froggatt et al. 2006; Street 2004). Spilsbury and Meyer (2001 p. 10) have argued that such methods are “based on the realities of practice, and reflect…issues of immediate relevance to practitioners”.

Participation by aged care staff in a critical research agenda enabled them to explore how their practices support dominant interests by examining taken-for-granted assumptions and habitual ways of practicing (Kinetchoe & McLaren 2008). Collaboration and reciprocity underpin the participation of the researcher and practitioners in a critical action research endeavour so that it is conducted “with and for people” (Meyer 1993 p. 1069) as opposed to ‘on’ people. The democratic agenda of action research provides an opportunity for staff, who may have different levels of status in an organisation (e.g. Registered Nurses (RNs), Enrolled Nurses (ENs) and PCAs) to come together. This project was conducted in the SCU, where staff had not been previously presented with an offer to meet regularly with the intention of interrogating their care practices. This situation is perhaps not surprising given that other literature has identified RACFs as hierarchical environments (Jervis 2002; McInerney et al. 2009) where PCAs and nursing staff may have limited engagement with each other beyond the provision of technical/functional care to residents (Ersek et al. 2000).

Through collaboration, dialogic relations can be developed, providing opportunities for participants to recognise that they share mutual concerns, and in turn develop a sense of ownership of the problems in their practice. This is an empowering process because it provokes people to take responsibility for their “own emancipation” (Carr & Kemmis 1986, p. 204) and opens up possibilities for strategic action. Through critical reflection on issues and data, participants in critical action research move through cycles where they plan, implement and evaluate action aimed at improvement, which can then result in replanning in pursuit of the same aim. A diagrammatic representation of the action research process is provided in Figure 1.
Action research is recognised as assisting the translation of knowledge/research into practice, thus reducing the separation between theory and practice (Waterman et al. 2001; Street 2003). The movement between action and reflection can facilitate the development of knowledge and theory that is derived experimentally, so that locally relevant strategies for implementing evidence into practice can be developed (Waterman et al. 2001, p. 12).

1.4 Structure of the thesis

As noted, this thesis chronicles the journey of a group of aged care staff from a dementia SCU as they engaged with me in a critical action research process to implement strategies supporting the delivery of a palliative approach to care in the SCU. I have attempted to present the activities of the project in a sequence that is faithful to the conduct of the research, while at the same time representing a coherent account. I believe that it is important for the reader to gain a sense of how the aged care staff in this project engaged with the research data and developed roles as co-researchers through the process. Therefore, some chapters in the thesis are quite dense and contain multiple sources of data. The link between action, research and knowledge generation creates a sense of continuity within and between the action research cycles (Kemmis & Wilkinson 1998); at times extricating the end of one cycle from the beginning of another was challenging. Apropos the collaborative nature of critical action research and the often intense relationships that are
developed with participants as they engage in action in practice (Herr & Anderson 2005), the process of actually writing this dissertation has been at times akin to assembling a jigsaw of thousands of pieces. I have attempted to capture the dynamic and often fluid nature of the change process, while explicating the incremental gains and struggles of the participating staff members.

Chapter 2 presents a review of the literature published prior to 2008. This literature has informed the development of the study and its direction. Post-2008 publications have been integrated into the discussion sections of Chapters 5 to 10 to further substantiate the findings. The current and future demographic profile of Australia’s population with reference to dementia are discussed initially in Chapter 2, followed by an overview of the significant changes that have occurred in the aged care system during the past two decades. This first section of the review provides an account of the conditions shaping the practices of RACF staff. Next, the impact of dementia on the RAC sector and implications of the dementia trajectory are discussed in addition to the applicability of contemporary palliative care for people with dementia. Key concerns and issues relevant to the translation of evidence into practice in the RAC setting are canvassed to support the delivery of an evidence-based palliative approach to care for people with dementia.

In Chapter 3 the theoretical foundations underpinning critical action research are examined. The relevance of critical theory and in particular, the work of Jürgen Habermas to the research, is discussed. Key strategies supporting this critical research agenda and considerations around the notions of enlightenment, empowerment and emancipation are presented. The contributions of post-modernism to the critical research agenda are also briefly discussed. Subsequently, a more detailed rationale for the use of critical action research to address the study’s questions is provided, as well as the practical implications of implementing action research and monitoring change.

Chapter 4 sets out the research design, providing an overview of the structure of the study, data collection and analysis techniques. Issues of validity and ethical conduct of the research are addressed and the research setting and staff members from the dementia SCU who formed the Action Research Group (hereafter called “ARG”) are introduced.
The study unfolded in three stages. **Stage One**, titled ‘Preliminary Investigation: A facilitated Engagement’, is examined in Chapters 5 and 6. Chapter 5 introduces the processes for setting up a collaborative dialogue with ARG members and reports on the findings from preliminary discussions with members about how they understand their practice and the provision of a palliative approach on the SCU. Consultation with the project steering committee about the preliminary concerns of the ARG is reported. Chapter 6 reports on the first action cycle designed to collect comprehensive baseline data to further explore concerns raised by the ARG in their preliminary discussions. It reports the first level analysis of the baseline data and the reflections of ARG members. The chapter traces members’ emerging critical analyses of previously unrecognised interests and conditions that have constrained the delivery of a palliative approach on the SCU.

**Stage Two**, titled ‘Emerging Empowerment’, explicates ARG members’ growing sense of ownership over the research process and empowerment as they explored possibilities for change. This stage is captured in Chapter 7. Members’ intense engagement in collecting data and their action to develop intervention strategies aimed at improving the delivery of a palliative approach are presented. Processes for gaining support for change, consulting the steering committee and tentatively finalising plans of action are discussed.

**Stage Three** of the project, titled ‘Reconfiguring practices: engaging in the politics of change’, traces the ARG members’ attempts to implement change that would support the delivery of a palliative approach to care on the SCU. Chapters 8 and 9 detail how members took action, collected and analysed data, and reflected on the outcomes. These two chapters chart the politics of care on the SCU, the powerful conditions that shape and reshape how care is constructed and the tensions for staff members engaging in change processes within a setting that is framed by traditional hierarchical power relations.

In Chapter 10 key changes in the understandings, practice and relationship of staff members are discussed. Future directions for action and research emerging from the study are presented. The chapter concludes with my reflections about participating in a critical action research project and a consideration of the limitations of this study.
Chapter 2: Literature Review

2.1 Background

The growing recognition of the need to provide palliative care for people with dementia in RACFs brings with it numerous social and economic challenges (Robinson et al. 2005b). Abbey (2006 p. 57) has argued that “our thinking and preparedness” to provide palliative care for people in RACFs who have progressive conditions such as dementia, is lacking. While most people with dementia in RACFs will undergo disability and decline leadingly inevitably to death, both their care and deaths are too often poorly managed (Abbey et al. 2006). Of particular importance to this study is the emerging body of research investigating strategies for developing staff practices around palliative care for people with dementia in RACFs. The intention of this chapter is to provide a review of the literature available prior to 2008 that traverses the fields of palliative care, dementia and RAC to background the study’s inception. Later research relevant to the project has been incorporated into the discussion sections of Chapters 5 to 10.

As noted, the provision of care for people with dementia is complex, and there is little research into strategies for practice development. To quantify this gap in the literature I conducted a series of literature searches across the electronic databases of CINAHL, PUBMED, MEDLINE, APAIS, PsychINFO. Keywords used in the searches included: dementia, cognitive impairment, Alzheimer’s, palliate*, palliative approach, aged care, nursing homes, residential aged care facilities and long term care. Contained within Appendix 1 is a matrix of literature searches and results conducted at the beginning of this project. The literature derived from these searches and subsequent hand-searching of journals, the Cochrane Library and the Australian Digital Theses program informed the study’s development and direction. My initial literature searches spanned 1994 to 2005. During this period literature relevant to the provision of a palliative approach to care in aged care and dementia care reflected the emerging status of this area of research. When conducting the literature review no studies were excluded on the basis of design, provided they were relevant to the research question. Studies that were located in specialised palliative care environments or hospital settings were only included if they contained information seminal to the broader field of research with potential applicability to the aged care context. It is worth noting that a significant proportion of research that has revealed
the complexities of providing a palliative approach to care for people in aged care environments has been written since the commencement of this study. In particular a growing body of research that emerged between 2005 and 2008 has focused on the translation of evidence into practice to enhance the care of older people both with and without dementia. Studies were included in this review that highlighted innovations in aged care practice and offered guidance about how to address some of the complex contextual factors that can undermine the development of evidence based practice.

This chapter begins with a brief overview of demographic changes in Australia. Next, significant changes that have occurred within the aged care system over the past two decades are discussed, to position the project within an historical context and highlight some of the long-standing issues affecting the contemporary provision of care for people with dementia. Characteristics of the dementia trajectory are then discussed to provide a rationale for conceptualising the care of people with dementia through the lens of a palliative approach. Key concerns about the provision of appropriate palliative care for people with dementia are raised, followed by consideration of policy developments within Australia that have recognised the need to better integrate palliative care and aged care practice. The development of the Guidelines (ADoHA 2004) as a key strategy aimed at enhancing evidence-based quality care for people in RACFs is then considered. The final section of this review discusses issues in the translation of evidence into practice in the RAC setting, as well as strategies that may provide opportunities for RACF staff to develop their practices around an evidence-based palliative approach for people with dementia.

2.1.1 Population ageing and implications

Australia, like all developed and many developing nations, has an ageing population and this trend is set to continue in the future (Gibson 1998; Knapp et al. 2007). Sustained low birth-rates and increased life expectancy at birth have resulted in the Australian population ageing both structurally and numerically (ABS 2008). In 1967, the proportion of people aged 65 years and over comprised 8.5% of the Australian population (Access Economics 2009a). In 2007, this cohort accounted for 13% of the Australian population (ABS 2008). This proportion is projected to increase to 23% by 2056 (ABS 2008). From 2001 to 2021 Australian society will experience an increase of approximately 2.2 million people aged over 65 years (ABS 2002, 2000).
The proportion of people aged 85 years and over in the Australian population will undergo the most substantial change. In 2007, 1.6% of the Australian population was aged 85 years or over and projections indicate that this proportion will increase to 4.6% in 2056 and 6% in 2101 (ABS 2008). According to a report authored by Knapp, Comas-Herrera, Somani and Banerjee (2007), the growth rate of Australia’s population aged over 80 years will increase 400% by 2050, this being one of the greatest predicted changes among high-income countries. It is the speed with which the proportion of people 80 years and over will grow that confronts policy makers and service providers in the Australian aged care system (Gibson 1998). Of particular concern is the increase in the prevalence of age-related diseases and the resultant dependency of people both in Australia and internationally (AIHW 2006a).

Dementia is primarily associated with old age (AIHW 2006b). With the social and medical advances of the 20th century, the proportion of people now living longer with neurodegenerative diseases, in particular dementia, is projected to increase rapidly (AIHW 2004, 2006a; Access Economics 2005). One study has estimated that the likelihood of being affected by dementia doubles every 5.1 years after the age of 65 (Henderson & Jorm 1998). Dementia is a syndrome caused by more than 70 conditions and is characterised by declines in language, memory, perception, personality and cognitive skills (AIHW 2004, 2006b). Alzheimer’s disease causes between 50 and 70% of dementia cases (AIHW 2006b; AIHW 2004; Henderson & Jorm 1998), with dementia of vascular origin considered to be the second most common form (AIHW 2006b).

Despite dementia being recognised as “one of the biggest health problems facing Australia” (Jorm 2001, p.1), there is no one single data source that can be used to provide prevalence estimates for the Australian population (AIHW 2006b). There are however, many data sources that can be used to build a picture of dementia in the community, albeit with limitations because of problems in diagnosis, assessment practices of health professionals, stigma, willingness to report a diagnosis, and the ways in which different sources of data are collected (AIHW 2006b). Moreover, national data sets (e.g. National Health Survey) contain information about dementia not readily separable from other information about cognitive impairment and behaviour (AIHW 2006b). The only source of information about people living in cared-for accommodation nationally is data collected via the Survey of Disability Ageing and Carers (SDAC), and methods of reporting may underestimate the
prevalence of dementia (AIHW 2006b). Despite these limitations, it has been estimated that 44% of people with dementia in Australia are aged between 75 and 84 years, and 37% are 85 years and older (AIHW 2006b, p.55). Access Economics (2005) estimates that in 2005 there were around 52,000 Australians diagnosed with dementia. It is predicted that by 2050 there will be over 175,000 new cases every year. Undoubtedly, these statistics support a need for research into the provision of care for people with dementia living within the community and in RACFs. The association between dementia and disability further highlights the importance of research that investigates strategies to develop appropriate evidence-based care.

2.1.2 The changing face of residential aged care: emergence of economic rationalism

A range of funding and legislative changes have taken place since the Australian Government’s role in aged care began in the 1950s (Courtney et al. 2004; Gibson 1998). Recently, it has been suggested (2002, p.228) that the roles of RAC staff, in particular RNs, have been subject to substantial change, derived largely from the introduction of the Aged Care Act 1997 (Commonwealth Department of Health and Ageing 1997). However, the Aged Care Act 1997 (Commonwealth Department of Health and Ageing 1997) brought about some of the most significant changes to the structure and organisation of care in RACFs. Rather than providing a comprehensive background to the structural reforms of the RAC sector, Sections 2.1.2.3 – 2.1.2.5 contain an overview of the major changes that have occurred and implications of these changes on the capacity of staff to meet the need of people with dementia.

2.1.2.3 Structural reform of the sector and increasing dependency in RACFs

At a sector-wide level, the Aged Care Act 1997 (Commonwealth Department of Health and Ageing 1997) pursued policy objectives consistent with earlier aged care reforms that focused on the expansion of community-based care (Gibson 1998). The progressive deinstitutionalisation of Australia’s aged care program markedly changed the profile of persons entering and domiciling in RACFs. The increasing dependency of people being admitted to RACFs, coupled with a progressive decline in admissions to the lowest levels of dependency (Andrews-Hall et al. 2007) has meant that by the time older people, including those with dementia, require admission to long-term care, their level of disability and care requirements are significant. Data available about dementia in RACFs at the commencement of this
study indicated that 72% of people requiring the highest levels of institutional care comprised people with dementia, while 60% of those requiring the second-highest level of care also had some degree of dementia (AIHW 2006b).

Another key structural change introduced by the Aged Care Act 1997 (Commonwealth Department of Health and Ageing 1997) was the amalgamation of the former hostels (low care) and nursing homes (high care) into one RAC system (Courtney et al. 2004). Supported by the introduction of the “Ageing in Place” policy, the new RAC system enabled older people to remain in the same location as their care needs increased, without having to be transferred to another facility (Gibson et al. 2002). Reflective of the higher dependency of people in RACFs remaining at one care location, as of 30 June 2005, almost 87% of residents exited permanent care via death, compared to 76% in 1999 (Andrews-Hall et al. 2007).

Similar results have been reported in the US, where it is estimated that 67% of Americans with dementia will die in a nursing home (Volicer 2005, p.6). In line with these trends RACFs in Australia have been identified as functioning like “de facto hospices” (Cooper & Glaetzer 2004) with similar observations having been made overseas (Froggatt et al. 2006; Engle 1998; Teno 2003; Wowchuk et al. 2006).

2.1.2.4 Impact of regulation on RACFs

A key regulatory change introduced by the Aged Care Act 1997 (Commonwealth Department of Health and Ageing, 1997), was the Resident Classification Scale (RCS). The RCS became the single instrument for funding RACFs in Australia and was the cornerstone of the new quality-monitoring system that was introduced in the sector. RAC provider funding was dependent on and adjusted according to the level of care delivered to residents, as reflected in the RCS documentation completed by aged care staff (Jeong & McMillan 2003; Rosewarne 2002). Consequently, the practices of aged care staff (especially RNs and ENs) have been profoundly reshaped around documentation requirements (Jones et al. 2002; Jeong & McMillan 2003). Residents with high care needs would be placed in a category between RCS 1 – 4 (equivalent to nursing home care) while resident in categories RCS 5 – 8 required low care (equivalent to hostel care).

To ensure that RACFs met newly-introduced national Accreditation Standards and to discern if resident care was consistent with the level of funding claimed (Rosewarne 2002), RCS documentation was annually reviewed by representatives from the
accreditation agency through a process known as “validation” (Rosewarne 2002). As a corollary of the constant need to attend to documentation, RNs have been described as having a predominantly “managerial function” (Jones & Cheek 2003) that supports organisational economic and regulatory imperatives at the expense of nursing hours in direct resident care (Richardson & Martin 2004; Martin & King 2008). Changes to the role of nursing staff in RACFs is of key concern, as increases in the dependency of residents and greater proportions of people with dementia suggest a need for highly-skilled nursing care.

2.1.2.5 Staffing

Staffing is a major area of concern within the RAC sector in Australia and overseas (Gray 2001a, 2001b; Venturato et al. 2006; Harrington et al. 2000; Keenan & Kennedy 2003; Kash, 2006). It is a complex issue, influenced by a range of factors (Venturato et al., 2006; Gray 2001b; Hogan 2004). Some of the most significant changes to staffing in RACFs were brought about by the introduction of the Aged Care Act 1997 as it contained no firm stipulation about staff numbers or skill mix in RACFs (Angus & Nay, 2003). Rather it only required that a provider “maintain an adequate number of appropriately-skilled staff to ensure that care needs of care recipients are met” (Aged Care Act 1997, Pt4.1/ Div 54.1). Thus, staff-to-resident ratios and the composition of staff qualifications in a RACF were left to the discretion of the provider and were no longer closely tied to funding (Angus & Nay 2003; Venturato et al. 2006). Angus and Nay (2003 p.134) have argued that increased proportions of unregulated care staff (meaning PCAs) is reflective of economic rationalist agendas that have engulfed aged care. Accordingly, these dominant interests fail to adequately acknowledge the complex needs of older people (Angus & Nay 2003).

Studies suggest that the deregulation of staffing has enabled providers to employ a cheaper but less-highly-skilled workforce and led to an overall reduction in staff numbers (Nay 2004; Uren 1996; Chandler et al. 2005). Supporting these claims, Australian National workforce data indicate that PCAs accounted for 59% of RACF employees in 2003 and that this had increased to 67% by 2007 (Martin & King 2008). Concurrently, there has been a reduction in the numbers of RNs in the sector from 21% in 2003 to 16.8% in 2007 and ENs from 13.1% to 12.2 % respectively (Richardson & Martin 2004; Martin & King 2008). The implications of changes to the staffing profile of RACFs has meant that high demands have been placed on
nursing staff to supervise PCAs in addition to clinical and documentation responsibilities.

Despite the economic advantages to aged care providers in employing a predominately cheaper workforce, there is concern about the capacity of staff in the sector to meet the complex care needs of an increasingly-dependent resident population (Cooper & Mitchell 2006; Cooper & Glaetzer 2004; Venturato et al. 2006; Angus & Nay 2003; Parker & McLeod 2002). At the commencement of this study, the influence of skill mix on care provision had not been comprehensively explored (Spilsbury & Meyer 2001). Equally, there was a paucity of research exploring the greater role of PCAs in providing direct care to people with dementia and the associated implications for the delivery of a palliative approach to care. What is evident within the published literature is that the care needs of people with dementia in RACFs and their family caregivers are significant and challenging. Issues associated with recognising dementia as a terminal condition are explored in the next section.

2.2 The dementia trajectory and implications for care provision in RACFs

2.2.1 Dementia: a terminal condition

A central interest of this project lay in developing palliative care practices of RACF staff in caring for people with dementia. It is therefore important to consider the literature that supports the view that dementia is a terminal condition. It is accepted that on average people with dementia have a life expectancy of 7 to 10 years after diagnosis (Clark 2000; Wolfson et al. 2001; Larson 2004; Walsh et al. 1990; Warner & Butler 2000). There remains debate in the literature as to whether people die “of” or “with” dementia (Thomas et al. 1997; Burns et al. 1990; Whitehead & Hunt 1982; Molsa 1986; Olichney et al. 1995; Fabiszewski et al. 1990; Kammoun et al. 2000; Agüero-Torres et al. 1999). Nonetheless, as Small, Froggatt and Downs (2007 p.7) have pointed out, what is clear is that “dementia heralds a biological process leading to death”. Research that has reported on the characteristics of the dementia trajectory is important to this study as it provides compelling evidence highlighting the need for palliation.
2.2.2 Characteristics of the dementia trajectory

As already noted, research investigating the features of the dementia trajectory was limited at the commencement of this study. Mitchell et al. (2006) have pointed out a range of methodological limitations in the current body of literature. Most notable limitations include small sample sizes; retrospective analysis; samples restricted to hospital settings; and reliance on data from secondary databases/sources (Lamberg et al. 2005; Mitchell et al. 2004a; McCarthy et al. 1997; Lloyd-Williams, 1996; Ahronheim et al. 2000). Despite these limitations, a number of studies have been valuable in contributing to understanding the symptom burden experienced by people with advanced dementia.

Research (McCarthy et al. 1997; Mitchell et al. 2004a) has reported that individuals dying of dementia have symptoms and health care needs comparable to those of cancer patients, however, individuals with severe dementia have been reported to endure symptoms (e.g. low mood, pain, confusion, urinary incontinence and loss of appetite, pressure ulcers), for relatively longer periods of time prior to death (McCarthy et al. 1997). Other studies have also reported considerable symptom burden experienced by people with dementia warranting palliation (Lloyd-Williams 1996; Volicer et al. 1994; Mitchell et al. 2004b). Covinsky et al. (2003) published the first empirical data that illustrated people with cognitive impairment experienced a gradual process of decline whereby, two years prior to death, they were found to be fully-dependent across four major functional measures\(^1\). Based on these findings, it was argued that “prolonged and progressive dwindling marks the end-of-life course” for people with dementia (Covinsky et al. 2003, p.495). Others (O'Connor 2004) have also recognised the importance of having care systems and models of care that will accommodate people who undergo protracted deterioration.

Over a decade ago Engle (1998) asserted that the provision of appropriate and responsive care for people in RACFs, including people with dementia, relied on a shift in the focus of care to acknowledging the presence of a “living-dying” continuum. This shift, it was argued, could transform the focus of health care professionals to “consider the quality of living-dying rather than the quality of life” (Engle 1998, p.1172). Such a conceptual shift with respect to the care of people with dementia has however largely been thwarted by a failure of health care professionals and family caregivers to recognise dementia as a terminal condition (Robinson et al.,

\(^1\) Bathing, eating, mobility and continence (Covinsky et al. 2003, p. 496).
2005b). Mutragh et al. (2004 p.40) have explained that in most non-cancer conditions, dementia being a primary example, the “entry re-entry” death trajectories mean that there is no clearly-defined terminal phase. Hence, with a more ambiguous dying trajectory compared to other terminal (especially malignant) conditions (Brenner 1999; Hanson et al. 2002), as well as difficulties with diagnosis and estimating prognosis, means that the relationship between dementia and dying both conceptually and practically has not been overtly recognised (Robinson et al. 2005b; Mitchell et al. 2006; Ahronheim et al. 2000; Albinsson & Strang 2002).

2.2.3 Recognition of dementia as a terminal condition

Research investigating care provision for people with advanced and end-stage dementia has reported that inappropriate interventions and overly-aggressive treatment practices of health care professionals suggest a lack of awareness or acknowledgment of dementia to be a terminal condition (Mitchell et al. 2004a; Morrison & Sui 2000b; Hanrahan & Luchins 1995). Literature (Hsu et al. 2005) suggests that there are gaps in the knowledge of aged care staff about dementia that may contribute to poor management of care and inappropriate interventions. Additionally, nursing assistants (PCAs) have identified their needs for further training opportunities, more information about dementia and ways of improving their communication and behaviour management skills (Burgio & Burgio 1990; Mass et al. 1994; Morgan 1996).

Qualitative research has revealed that family members also do not consider dementia as a terminal condition. Chung (2000) reported in her qualitative study that family caregivers have predominantly “lay” understandings about dementia, based largely on personal experience. Similarly other research (Caron et al. 2005b) has reported that family caregivers of people with severe dementia have limited understanding of the natural course of dementia. Focus groups conducted with 28 family caregivers in a qualitative study in the US demonstrated that most of the participants were unable to conceptualise the trajectory of dementia, with the dying process reported as “unrecognised” and “disguised” (Forbes et al. 2000, p.257). Most family caregivers believed that their relative would die of a sudden medical event (e.g. heart attack or stroke) rather than a more progressive process of deterioration (Forbes et al. 2000) and hence, tended to “disassociate” their relative’s dementia from death (Gessert et al. 2001). Not surprisingly, family caregivers have been identified as requiring
improved knowledge and information about the dementia trajectory (Arai et al. 2008; Albinsson & Strang 2003; Aggarwal et al. 2003).

Current research suggesting that family caregivers and aged care staff do not associate dementia with death begs the question as to what the possibilities are for initiating a palliative approach to care. Arguably, the recognition of the need for palliative care is enhanced by knowledge of the dementia trajectory. Therefore, this project offers an important opportunity to explore ways of working with staff and family caregivers to enhance their knowledge about dementia. The importance of investigating such strategies is highlighted by Small, and colleagues (2007 p.7) who eloquently make the point that, “to be living with dementia is to be dying with dementia”. With this in mind, insights from sociological literature suggest that cultural mores also shape the way that people, such as family caregivers and RACF staff, conceptualise dementia and death.

2.2.4 Socio-cultural considerations: dying, death and dementia

A number of broad cultural factors have hindered palliative care from being embraced within society and in health care settings. Notwithstanding the debates around economies of care and cost-sharing (O'Connor & Pearson 2004), death is viewed within health care and the wider society as a “medical defeat or failure” (Ashby et al. 2005). Social anxiety about death prohibits an acceptance of mortality. With the emergence of medical dominance in Western society, aligned with values of modernity such as technical progress, individual empowerment and control over one’s world (Valentine 2006; Giddens 2006); death challenges medicine’s most fundamental goals of control and/or cure (McInerney 2007, p.392). Accordingly, Valentine (2006) has asserted that modern society has difficulty in reaching a resolve with human mortality. McInerney (2007), in her analysis of the “requested death movement”, has highlighted the social unacceptability that is associated with dying and how “grotesque” processes that accompany the loss of control over the body are understood as fundamentally altering the identity of the person.

Modernist values of contemporary society are not only challenged by death but also by disability and “defective bodies” (Wolfensberger 1994, p.400). The gross cognitive and physical deterioration associated with advancing dementia (such as incontinence, reduced communication skills, the inability to feed oneself and in later stages, loss of mobility, loss of verbal skills, limb contractures and the adoption of a
foetal position) has led it to be described as a “living death” (Small et al. 2007, pp. 103-104). The loss of physical and cognitive functioning has been associated with a loss of self-identity or a “dismantling” of the self (King 1997, p.277), with medicine ineffective in countering this process.

More recent advances consider the construction of the enduring nature of personhood beyond loss of cognition (Kitwood 1990, 1993a, 1993b, 1997). Kitwood (1997) has proposed person-centred care that continues to value the person’s identity as an approach to people with dementia. It relies on formal caregivers and those close to the person with dementia having intimate knowledge of the person’s life history, personality and lifestyle, so that care can be provided that supports the person’s identity and values their individuality (Kitwood 1997). Despite these developments, research suggests that the physical and cognitive deterioration and loss of control associated with advancing dementia have meant that the condition continues to be stigmatised as socially unacceptable (Zimmermann 2004; Dobbs et al. 2008). The socio-cultural context within which death and dementia are ascribed meaning, have resulted in neither death nor dementia being readily embraced within society.

Despite death being a “common occurrence” (O'Connor & Pearson 2004, p.32) in nursing homes, evidence suggests that it remains hidden with infrequent discussions on the topic (Forbes et al. 2000; Gessert et al. 2001; Komaromy 2000). Dying and death have undergone gradual privatisation, sequestered by institutions such as RACFs, and removed from public life (Froggatt 2001a; McInerney 2007). Consequently, Western societies have become largely devoid of positive death rituals (O'Gorman 1998). Komaromy (2000) has reported that institutional practices in nursing homes, which support the invisibility of death, contribute to a denial of dying. Forbes and colleagues (2000 p.256) have argued that in a social and institutional culture where death is concealed, considered taboo and largely “excluded from public and private discourse”; family caregivers of people with severe dementia have been required to make complex decisions in the absence of open and supportive communication. Consequently, there is an increased risk that people with end-stage dementia will be subject to inappropriate treatment, as family members feel compelled to “treat the ‘treatable’” (Forbes et al. 2000, p.255).

Death in RACFs however, is not an uncommon process. Arguably, the way that death has been framed by dominant cultural imperatives and practices as a hidden phenomenon (Komaromy 2000) while simultaneously as highly “normalised”
(O’Connor & Pearson 2004; Komaromy 2000), undermines opportunities for the provision of palliative care. O’Connor and Pearson (2004) have argued the case for openly acknowledging death and dying in RACFs at policy and practice levels. More recently, developments within the field of palliative care have seen the emergence of a more generalist model of care for people with life-limiting conditions and a gradual movement toward greater death awareness in society.

2.3 Expanded applicability of palliative care

Any discussion of the development of palliative care in Australia, as Rumbold (1998) has noted, needs to take into account overseas experiences. Policy- and decision-making around the direction of palliative care in Australia have been informed by developments in countries such as the UK and the US (Rumbold 1998).

2.3.1 Evolution of palliative care

The modern hospice movement originated in the UK and gained momentum when St Christopher’s Hospice was established in 1967 (Clark 1998). The movement was based on a set of principles developed in response to the perceived needs of terminally ill cancer patients; to date this remains integral to the general understanding of palliative care, even though its definition has undergone dynamic change (Aranda 1998). The principles espouse that palliative care:

- is an approach to care emphasising living and acknowledging death as an intrinsic part of life;
- is centred on the person and the family as client and emphasises the client’s role in the direction of care;
- utilises a multidisciplinary team in recognition of the need to offer care that is holistic and meets the complex needs of the dying person and family; and

From the 1960s in the UK, 1970s in the US, and Australia in the early 1980s, palliative care was used to describe the care of people dying with cancer (Magno 1990; Meghani 2004; Kellehear 2003). In the US, fiscal concerns largely underpinned the acceptance of hospice care into the health care system and defined how palliative care was understood. Conditions for hospice benefits to be paid to health care institutions included “a diagnosis of an incurable malignant disease, [and]
a prognostication of life expectancy as 6 months or less” (Meghani 2004 p.154). In the UK (Katz et al. 1999; Komaromy et al. 2000) and Australia (Maddocks et al. 1996), palliative care has historically been synonymous with hospice- or terminal-care associated with cancer. The relevance of palliative care for non-malignant conditions was recognised during the 1980s in the UK and the US (Wilkes 1980). Changes such as an ageing population, increasing life expectancy, changing illness trajectories, and more sophisticated medical, surgical and pharmacological interventions, “challenged the historical view of palliative care” (Meghani 2004 p.153). As a result, conceptual distinctions emerged between palliative care and terminal care in the 1990s. These changes in understandings were evident in the World Health Organization’s (WHO) (1990) definition of palliative care as:

…the active total care of patients whose disease is not responsive to curative treatment…The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti-cancer treatment.

Over the subsequent decade, the definitional constructs of palliative care were further challenged through a growing dialogue around issues of equity and need. Research into the needs of people dying with non-malignant conditions added impetus to the argument that there needed to be greater equity in accessing palliative care (Harris 1990). A number of studies demonstrated that people with non-cancer life-limiting conditions such as congestive cardiac failure (Murray et al. 2002), renal failure (Weisbord et al. 2003), chronic obstructive pulmonary disease (Claessens et al. 2000), motor neuron disease (Kristjanson et al. 2003), and dementia (Mitchell et al. 2004a), had symptoms and other needs which could be met by palliative care.

With research indicating that people with non-malignant conditions had unmet needs that fell within the remit of palliative care, there was a recognition that the provision of palliative care should be driven by need, rather than life expectancy or diagnosis (Field & Addington-Hall 1999). Therefore, the WHO amended the 1990 definition of palliative care and in 2002 (World Health Organization 2002) defined it as:

An approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and
impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

This definition shifted away from the early-1990s’ cancer-orientated late-stage model of care to a more inclusive and flexible form of service delivery (Sepulveda et al. 2002; Clark & Seymour 1999; Addington-Hall & Higginson 2001). Thus, contemporary palliative care became relevant for people with a variety of life-limiting conditions other than cancer; including chronic obstructive pulmonary disease (COPD), human immunodeficiency virus - acquired immune deficiency syndrome (HIV-AIDS), end-stage organ failure, and neurodegenerative diseases such as Parkinson’s disease, Alzheimer’s disease and other dementing illnesses (Currow & Nightingale 2003; Kristjanson et al. 2003; Sepulveda et al. 2002; Gibbs et al. 2002; Lo & Woo 2001). The principles of palliative care were recognised as being applicable as early as possible in the disease process (Sepulveda et al., 2002). Additionally, central to the provision of palliative care was the participation of a multidisciplinary team which could collaborate in holistic care and decision-making for individuals and their families (Meghani 2004; Maddocks 2003). These conceptual transformations have resulted in the term “palliative care” being expanded into a model of care which has greater applicability to the non-specialist area.

2.3.2 The spectrum of palliative care

From the early 1990s palliative care in the UK became diversified to become a spectrum of care, reflected in both policy and research (National Council for Hospice and Specialist Palliative Care (NCHSPCS) 1995). Subsequently, delineations between ‘specialist palliative care’, ‘palliative interventions’ and a ‘palliative approach’ have emerged in policy documents (NHS Executive 1996; PCA 2005b) and research (Clark 1993; Kristjanson et al. 2003; Hughes et al. 2004; Addington-Hall 1998; Froggatt 2000). Of central importance to this study is the palliative approach also known as the ‘generalist approach’ to palliative care (Davies & Seymour 2002). Drawing on a 2001 briefing document from the National Council for Hospice and Specialist Palliative Care, Davies and Seymour (2002 p.14) provide the following definition for this type of care, making a clear distinction from the specialist service.

General palliative care [is] palliative care provided by the patient’s and family’s usual professional carers as a vital and integral part of their routine
clinical practice. It is informed by a knowledge and practice of palliative care principles. A practitioner within a general palliative care service should be able to: access patient’s palliative care needs; meet those needs within the limits of their knowledge, skills and competence; know when to seek advice from or refer to specialist palliative care services.

There are several central concepts widely discussed in the literature that underpin a palliative approach. Firstly, it is viewed as an integral dimension to all clinical practice (Johnston 1999; Hughes et al. 2004; Addington-Hall & Higginson 2001). Kindlen and Sheena (1999 p.28) have stated that it “involves core skills for every clinician in health care”. Palliative Care Australia (2005b p.12) has asserted that it includes “primary care providers” such as general practitioners; community nurses; and staff of RACFs and multi-purpose centres. Secondly, there is agreement that a palliative approach is informed by palliative care principles and promotes these principles regardless of the illness type, stage, or setting of care (Kindlen & Walker 1999; Hughes et al. 2004; Johnston 1999; Addington-Hall & Higginson 2001). Thirdly, it is a proactive approach and responsive to the needs of people as their conditions progress, with an aim to improve the quality of life for individuals and their families including a focus on early care planning (Kristjanson et al. 2003; Kindlen & Walker 1999; Hughes et al. 2004; Addington-Hall & Higginson 2001). There is agreement in the literature that a palliative approach is supported by specialised palliative services (Addington-Hall 1998; Addington-Hall & Higginson 2001; Hughes et al. 2004). This support is often episodic rather than sustained, because the needs of the family, patient or staff may fall outside the scope of knowledge or skills of those providing a palliative approach to care.

Literature (Hughes et al. 2004; Addington-Hall & Higginson 2001; Kristjanson et al. 2003; Kindlen & Walker 1999) discussing the spectrum of palliative care often considers terminal or end-of-life care separately. Nonetheless, it is undoubtedly an important part of the palliative process and the journey of the person with a life-limiting illness. The NCHSPCS (1995 p.5) has stated that terminal care:

…usually refers to the management of patients during the last few days or weeks or months of life from a point at which it becomes clear that the patient is in a progressive state of decline.
Reflective of the need for a diversification of palliative care, a palliative approach has been recognised as an appropriate frame of care for people in RACFs who have non-malignant, life-limiting conditions such as dementia. The difficulty experienced by clinicians in identifying when a person with dementia requires palliation (Robinson et al. 2005b) has been linked to ‘cancer-centric’ models of palliative care that have relied on a well-defined terminal phase and identified as not appropriate for this client group (Froggatt 2001b). It is argued that dementia should be considered through a palliative lens from the point of diagnosis (Hughes et al. 2005). Taken from this perspective a palliative approach to care for people with dementia can be provided early within the illness trajectory. While these developments have been welcomed, evidence suggests that there are a number of key challenges to the practical application of this approach for people with dementia. The next section provides an overview of these challenges.

2.3.3 Issues in the provision of palliative care for people with dementia

Issues identified as impacting on the delivery of a palliative approach to care for people with dementia in RACFs in Australia and overseas include: deficits in RACF staff knowledge; problems with pain and symptom management; the use of overly aggressive interventions in the advanced stages of dementia; and a relative absence of advance care planning (ACP). As a manifestation of these difficulties encountered by RACF staff, it has been suggested that people with dementia in RAC settings receive ‘sub-optimal’ palliative care (Mitchell et al. 2004b; Sloane et al. 2003). The following sections explore these issues.

2.3.3.1 RACF staff knowledge about palliative care

In the context of providing a palliative approach for people with dementia, research suggests that RACF managers and staff lack knowledge about palliative care. Studies within Australia (De Bellis & Parker 1998; Clare & De Bellis 1997; Parker & De Bellis 1999), the US (Ersek et al. 1999), the UK (Katz et al. 1999; Froggatt 2000), Ireland (Whittaker et al. 2007) and Canada (Brazil & Vohra 2005) have identified the need for greater education about palliative care in the long-term care environment.

Several Australian studies carried out in the late 1990s examined RACF managers’ understandings of palliative care (Clare & De Bellis 1997; Maddocks et al. 1996; De Bellis & Parker 1998). Results indicated that these staff were able to demonstrate a reasonable understanding of the term “palliative care”, having associated it with
phrases such as ‘quality of life’, ‘holistic care’, ‘pain management’, and ‘psychosocial and emotional support for family and residents’. However, Clare and De Bellis (1997) pointed out that when the managers provided a profile of residents who were receiving palliative care, almost all were actually in receipt of terminal care. Likewise, Maddocks and colleagues (1996) concluded that palliative care in Australia was principally associated with terminal care and dying. This early literature suggested a dissonance between understandings and operation of palliative care in Australian RACFs. Studies examining nursing home managers’ understandings of palliative care in the UK have indicated that the majority (n=100) did not understand the principles or practice of palliative care (Katz et al. 1999). Other research has indicated that there is substantial ambiguity around the concept of end-of-life care as understood by nursing home managers (Frogtatt & Payne 2006).

More-recent Australian research has explored RACF staffs’ (e.g. RNs, ENs and PCAs) perceptions of palliative care through focus group discussions (Phillips et al. 2006). The findings indicated that while staff held some contemporary understandings of a palliative approach, they lacked what Phillips et al (2006 p.421) identified as a “palliative care language set”. Participants highlighted difficulties communicating with other professionals (e.g. General Practitioners (GPs)), feeling unprepared to facilitate sensitive conversations with residents or their family members, and desiring more opportunities to develop their palliative care skills (Phillips et al. 2006). Similarly, Ersek et al (2000) reported that nurses in the US had difficulty communicating with both physicians and nursing assistants (PCAs), while PCAs reported similar issues. Research in Ireland identified that PCAs mostly considered palliative care as synonymous with end-of-life care (Whitaker 2007). This study highlighted the need for improved knowledge generally for those staff members (PCAs) who are the “frontline” caregivers (Whittaker et al. 2007 p.41). McIlfatrick (2006) reported that a range of health professionals, including aged care staff, were uncertain as to when a palliative approach should be implemented in the course of an illness. With variable understandings among staff in RAC settings, strategies to operationalise a palliative approach have been recognised as requiring further research (Phillips et al. 2006). Other research has also identified aged care staff as needing more education about palliative care, including: how to talk with and support dying residents and their relatives, pain management, drug side-effects, and spiritual and cultural issues (Miskella & Avis 1998; Ersek et al. 1999; Phillips et al. 2007; Brazil & Vohra 2005; Froggatt 2000b). Pain and symptom management for
people with cognitive impairment has also received significant attention as an area requiring improvement for RACF staff.

3.2.3.2 Pain assessment and management

Research from the US, UK and Australia has reported that people with advanced dementia frequently experience pain which is poorly-assessed, under-recognised, and under-treated (Ferrell et al. 1995; Kovach et al. 2001; Horgas & Tsai 1998; Sengstaken & King 1993; McClean & Higginbotham, 2002). Research undertaken in the US (Ferrell et al. 1990; Ferrell et al. 1995; Bernabei et al. 1998) has indicated that residents in RACFs have high rates of untreated pain, with the presence of cognitive impairment a significant barrier to timely and accurate assessment and management (Ferrell et al. 1995; Huffman & Kunik 2000). While individuals with cognitive impairment are less likely to be able to identify pain and communicate their need for medication effectively, evidence has emerged in Australia (Abbey et al. 2004) and overseas (Kovach et al. 2001; Kovach et al. 1999) that suggests the needs of these people can be discerned through the use of appropriate assessment tools. Despite a number of tools (e.g. NOPAIN (Snow et al. 2004), PAINAD (Warde et al. 2003), Abbey Pain Scale (Abbey et al. 2004)) having been developed to improve pain recognition and documentation; poor levels of use and completion rates have been reported (Ferrell et al. 1995; Radbruch et al. 2000). The need for improved knowledge of nursing staff and physicians regarding the use of such tools, management strategies, and treatment is highlighted as a necessary precursor to improving the comfort of people with dementia in RACFs (Sloman et al. 2001; Kovach et al. 1999).

Additionally, research from the US and Canada reports that significantly less analgesia is prescribed and given to people with cognitive impairment compared to their cognitively intact counterparts (Kaasalainen et al. 1998; Horgas & Tsai 1998). Moreover, Morrison and Sui (2000a; Morrison & Sui 2000b) identified a general reluctance to use narcotic pain relief for people with advanced dementia in the acute setting, a finding supported in Evers et al.’s (2002) work. The literature on pain assessment and management for people with dementia suggests that there are significant problems in the translation of evidence into practice. Given the centrality of pain and symptom management to the provision of a palliative approach to care, this was identified as an important issue when setting up the study.
3.2.3.4 Aggressive interventions

In addition to the issues highlighted around pain management, it has been reported (predominantly in overseas literature) that people with dementia are more likely to undergo unnecessary and aggressive interventions than people without dementia, particularly at the end stage of life. A large amount of research reveals that people with advanced dementia are often subjected to burdensome treatments and interventions such as antibiotic administration (Morrison & Sui 2000b; Fabiszewski et al. 1990; Chen et al. 2006; Hurley et al. 1993), invasive laboratory tests, intravenous therapy, enteral feeding (Mitchell et al. 2004a) and transfer to an acute care setting (Lamberg et al. 2005; Travis et al. 2002; Travis et al. 2001; Mitchell et al. 2004b) with little or no therapeutic benefit. For example, research on enteral feeding has established that this intervention has little efficacy for individuals in advanced stages of dementia, but may have adverse impacts such as increasing the risk of aspiration (Finucane et al. 1999; Gillick 2000; Mitchell et al. 1997).

Within Australia, the issue of unnecessary transfers to the acute care setting has been identified as an area of concern (Caplan et al. 2006). Shega et al. (2002) have suggested that unnecessary interventions are often administered largely as a result of fears of regulatory sanction, inadequate knowledge of research evidence and a lack of effective culture change across all providers of health care for people with dementia. Such practices however, shift what Brauner, Muir and Sachs (2000) have termed the “risk-benefit ratio” and potentially violate the principles of comfort and relief of suffering that underpin palliative care philosophy (Aranda 1998; World Health Organization 2002).

3.2.3.5 Collaborative decision making

While people with mild dementia are able to participate in decision-making about their future care (Murtagh 2004), inevitably their capacity to effectively participate in these processes diminishes as their condition progresses. As dementia advances, decision-making becomes an increasing responsibility that aged care staff and family caregivers of people with dementia assume, which in the literature has been referred to as “progressive surrogacy” (High & Rowles 1995). ACP is one approach to enhancing decision-making about care in the context of future deterioration of a person. According to Taylor and Cameron (2002) ACP is a process of communication between a person with a life limiting illness (where possible),
members of his/her health care team, and family caregivers, with the intent of developing an expression of his/her wishes for future care. Numerous authors emphasise that the process of communication, rather than the completion of a written document, is central to ACP (Prendergast 2001; Martin et al. 2000; Taylor & Cameron 2002).

The majority of research about ACP has originated from the US (Molloy et al. 2000; Hines et al. 2001; Happ et al. 2002; Kolarik et al. 2002; Volicer et al. 2002; Teno 2007; Teno et al. 1997; Lamberg et al. 2005; Chen et al. 2006; Ramsaroop et al. 2007). At the time of the fieldwork for this study there was a growing body of research in Australia and the UK, the majority of which was exploratory/descriptive about ACP (Lyon 2007; Taylor & Cameron 2002; Squires & Barr 2005; Brown et al. 2005; Froggatt & Payne 2006; Caplan et al. 2006). Evidence (Molloy et al. 2000; Caplan et al. 2006) suggests that the articulation of goals and wishes for care are important determinants of the type of care received by people with and without dementia and may reduce the use of aggressive interventions at the end of life. On the whole ACP has not been well-implemented in the UK (2006) or Australia (Nair et al. 2000; Grbich et al. 2003; Grbich et al. 2005; Brown et al. 2005).

There is evidence to suggest that decision-making about the care of people in long-term care settings, including people with dementia, is challenging and may not be broached until a crisis event or end of life (Travis et al. 2002; Lamberg et al. 2005). Indeed, sub-optimal palliative care for people with dementia has been identified, by some, as related to a lack of collaborative decision-making processes between staff and family (Forbes et al. 2000; Caron et al. 2005a; Robinson et al. 2005b). As discussed in Section 2.3.2, a palliative approach to care is proactive and emphasises early care planning as a means to ensuring appropriate care (Kristjanson et al. 2003; Addington-Hall & Higginson 2001). Despite family caregivers being recognised as key stakeholders in decision-making processes with aged care staff (ADoHA 2006), barriers such as their knowledge of dementia and their role in decision-making have been reported in qualitative studies to limit the participation of family (Forbes et al. 2000; Caron et al. 2005b). Moreover, problems with communication and relationship development between staff and family as well as tensions about who has “control” over care processes (Bauer 2006; Hertzberg & Ekman 2000; Haesler et al. 2007) have also been identified as challenges to the development of collaborative partnerships. In recognition of these concerns research focusing on the development
of “relationship-centred” approaches to care has grown over the past decade (Nolan et al. 2004; Nolan et al. 2006). Additionally, other research has reported that GPs as well as aged care staff have difficulty initiating sensitive discussions with family caregivers (Wissow et al. 2004; Hawkins & Cartwright 2000; Phillips et al. 2006). These are important concerns in the context of providing a palliative approach to care for people with dementia. In the absence of collaborative relationships and proactive discussions about future care and treatment prior to the occurrence of the end-of-life phase, Robinson and colleagues (2005b p.137) have pointed out that “routine clinical care” can by default dominate the end-of-life care, often with adverse outcomes for quality of life and comfort.

Given the long-standing nature of some of the concerns highlighted above, in early 2000, there were a number of policy developments that embraced these concerns with an intent to improve the provision of appropriate and timely palliative care for people in Australian RACFs, including those with dementia. These developments have been influential in shaping the environment within which this project has been undertaken and thus will be briefly discussed below.

2.4 Developments supporting a palliative approach in RACFs

In Australia, the National Palliative Care Strategy (ADoHA 2000) provided a platform for policy developments that acknowledged the broadening intersection between aged care and palliative care. Endorsed in October 2000, it brought together governments (federal, state and territory), non-government organisations, and service providers with a stake in palliative care, through a range of initiatives to improve “access to and quality of palliative care service provision” (ADoHA 2000). Collectively these initiatives became known as the National Palliative Care Program, comprising four broad areas:

- Support for patients, family and caregivers throughout the community;
- Increased access to palliative care medicines in the community;
- Educating, training and support for the workforce; and
- Research and quality improvement for palliative care services (ADoHA 2000).

The federal government commissioned a number of projects as part of the “education, training and support for the workforce” initiative in the National Palliative Care Strategy. Of central importance to this study is the Australian
Palliative Residential Aged Care (APRAC) project that investigated how a palliative approach to care could be incorporated in RACFs for people with non-malignant conditions (Kristjanson 2005). The APRAC project was established as a material recognition of the “critical need for a palliative approach in residential aged care” (the Guidelines) (ADoHA 2004, p.4). Evidenced-based, best-practice guidelines were developed through the APRAC project; the first version being released in 2004 (ADoHA 2004) and a revised version endorsed by the National Health and Medical Research Council in 2005 (ADoHA 2006).

The development of the Guidelines (ADoHA, 2006) was a significant undertaking and a world first. Based on a systematic review of available evidence, 79 guidelines across 15 key areas were developed. However, it has been highlighted that they (ADoHA 2006) emerged from research that lacked a “high” level of evidence (Currow & Hegarty 2006). Qualitative research (exploratory/descriptive) and expert opinion have populated a substantial proportion of the literature and is supportive of the delivery of a palliative approach for people in RACFs (Froggatt et al. 2006; Hancock et al. 2006; Sachs et al. 2004). The type of questions addressed and the ways in which the evidence about a palliative approach to care has been generated have influenced the type and character of recommendations that have been made.

Within the introduction of the Guidelines it is stated that “they aim to prompt creative solutions that will be appropriate to the particular RACF in which a palliative approach is being applied” (ADoHA 2004, p.1). The Guidelines are a key resource that can contribute to the development of practice that will support a palliative approach to care and as such will be utilised in this study.

Following the development of the Guidelines, a nationally funded program was established to aid their implementation in RACFs (Currow & Hegarty 2006). In 2005, the Australian Government provided funding (USD 2.5 million) to Palliative Care Australia to raise awareness of the Guidelines and undertake an educational ‘roll-out’, via national workshops to promote their implementation across the residential sector (Kristjanson 2005; PCA 2005a). Despite the significant financial impetus behind the development and dissemination of the Guidelines (ADoHA 2004) there is a lack of rigorous, empirical evidence about the extent to which the Guidelines (ADoHA 2004) have been adopted and implemented within Australian RACFs. Of key concern to this project is the limited research focus on strategies to support RACF staff to implement an evidence-based palliative approach to care in
their facilities. Equally lacking is literature addressing how this may be best achieved for people with advanced dementia. These concerns are addressed in the following section.

2.5 Translation of evidence into practice in RACFs: competing tensions

On commencing this study there was limited published evidence suggesting effective strategies to guide staff in the implementation of evidence-based palliative approaches to care for people in RACFs or long-term care settings. A report to the WHO (Davies & Higginson 2004, p.30) highlighted the “lack of evidence from implementation research…[about]…effective methods for nursing or residential homes” to meet the needs of people dying from non-malignant conditions. Additionally, identified in the systematic review of the literature for the development of the Guidelines was the “growing need to look at the most effective ways of creating evidence-based practice and of efficiently and effectively disseminating the results of research and their applications to care” (ADoHA 2005, p.94). This study will contribute to developing strategies for use by aged care staff to facilitate the translation of evidence into practice, supporting the delivery of a palliative approach to care.

The question posed by this study, being what are the possibilities for aged care staff to develop their practices around a palliative approach to care for people with dementia and their family caregivers? was timely, given that the Guidelines (ADoHA 2004) had been available for 12 months prior to the beginning of fieldwork. Literature about clinical and best-practice guidelines highlights that they had largely been used as a key strategy to promote evidence-based practice across a range of health care disciplines and sectors (Richens et al. 2004). However, despite the growth of literature that has accompanied the evidence-based health care movement, there remains ambiguity as to the best strategies that will facilitate successful implementation of these Guidelines and for that matter, other forms of evidence, into practice (Grimshaw et al. 2004; Richens et al. 2004). From their review of research on guideline implementation, Grimshaw, Eccles and Tetroe (2004) reported that the dissemination of evidence alone and didactic approaches to staff education were unlikely to bring about change. Given that in general, studies about the implementation of guidelines to practice have been methodologically weak,
resulting in difficulty discerning which implementation strategies are of value, the most convincing evidence from the literature relates to the use of multi-faceted interventions, interactive education programs and clinical reminder systems (Dobbins et al. 2002; Dopson et al. 1999; Dopson et al. 2002; Grimshaw et al. 2001; Prior et al. 2008). However, further evaluation of such strategies is required. Within the literature the capacity of RACF staff to operationalise strategies to support the implementation of evidence about a palliative approach into practice has received scant attention. As will be discussed below, significant challenges to implementation exist, however innovations by some in the field provide important guidance about how some of these challenges can be negotiated.

2.5.1 Experience and expertise of RACF staff in evidence-based practice

Research suggests that RNs and other aged care staff across a number of settings may have limited experience of and access to evidence-based practice (Koehn & Lehman 2008; Fallon et al. 2006). Paraprofessional staff in long-term care (e.g. PCAs) are also considered less likely to be aware of research evidence compared to nursing staff (McConnell et al. 2007). In addition to access issues that limit staff knowledge of research evidence, McConnell and colleagues (2007), who investigated academic–practice partnerships to promote evidence-based practice in long-term care, reported that even the most practical evidence-based guidelines required interpretation and application that was augmented by local knowledge and expertise. In the practice development literature (Kitson et al. 1998), the importance of staff being able to recognise a sense of “fit” (Rycroft-Malone et al. 2004) between the evidence and their practice has received considerable attention as a crucial factor in the facilitation of translation. Hence, Kitson et al. (1998) argued that evidence should be considered more broadly to include a combination of research, clinical experience and patient experience. Rycroft-Malone et al. (2002 p.175) argued that “critical reflection, critique and debate” was important in developing knowledge of what works in practice for clinicians and clients. Yet other literature (Tuckett 2005; Bowers et al. 2001; Watson et al. 2006) has highlighted that nursing staff and PCAs in RAC settings have struggled to engage in processes of reflection and critique due to a lack of opportunities, often resulting from their privileging of a task-orientation to care and inadequate skills to engage in critically reflective practice.

There is evidence to suggest however, that when provided with opportunities, aged care staff can be assisted to engage in critical reflection to facilitate knowledge
translation (Booth et al. 2007; Fallon et al. 2006; Nolan et al. 2007c). Watson, Hockley and Dewar (2006) reported on a study to implement an end of life care pathway in eight nursing homes in the UK. They argued that working in a critically collaborative way, through an action research approach with staff, including PCAs, was essential in overcoming barriers to the implementation of best practice. Likewise, a project (Dewing & Traynor 2005 p.701) with dementia specialist care nurses working in the community, illustrated that an action research approach stimulated the participants to critically reflect on their practices, identify knowledge gaps and develop strategies for practice development. This research suggests the benefits of working with RACF staff in participatory and collaborative ways where participants become “practitioner researchers” of their own practices and contexts (Dewing & Traynor, 2005 p.701).

It is suggested that for staff in aged care settings to develop better understandings of evidence-based practices, they should be engaged in generating and identifying evidence (Pearson 2004; Tolson et al. 2006). Booth and colleagues (2007 p.952) supported this contention and highlighted that an action research methodology was successful in assisting gerontological nurses to explicate their previously unrecognised “tacit knowledge”. Accordingly, this process enabled staff members to augment more traditional knowledge sources (research), enhancing its translation into practice (Booth et al. 2007). The outcomes of the Booth and colleagues’ (2007) collaborative research project challenged the dominant hierarchy of evidence, imposed on aged care and other health settings, to meld “tacit” knowledge and clinical knowledge with research evidence to facilitate evidence-based practice. This more holistic approach to the implementation of evidence into practice is also paralleled in studies (Robinson et al. 2007; Robinson et al. 2005a; Lyon 2007) that have worked to explicate other contextual and political factors impacting on the capacity of aged care staff to develop best practice.

2.5.2 Contextual factors influencing evidence-based practice in the RAC setting

There is broad consensus that contextual factors influence successful implementation of evidence into practice, including evidence-based guidelines (Kitson et al. 1998; McCormack et al. 2002; Richens et al. 2004; Lee et al. 2002). Key contextual issues documented in Australian and international literature relating to workforce capacity, professional isolation, competing cultures of care and organisational hierarchies have
been recognised as inhibiting the development of evidence-based palliative care practices (Hasson et al. 2008; Cheek et al. 2004; Froggatt et al. 2002; Froggatt & Hoult 2002; Froggatt et al. 2006; Wowchuk et al. 2006, 2007; Abbey et al. 2006). These issues are addressed below.

2.5.2.1 Workforce capacity

Changes to the structure of the aged care workforce and regulation of the sector since the introduction of the Aged Care Act 1997 have been reported to increase the supervisory and documentation/administrative requirements of nursing staff, in particular RNs (Jones et al. 2002; Venturato et al. 2007; Milson-Hawke & Higgins 2003). The implications of regulatory and institutional interests on shaping the practice of nursing staff have been reported to diminish their ability to develop evidence-based practices (Robinson et al. 2007; Lindeman et al. 2002; Jones & Cheek 2003). While changes in policy have been successful in establishing an ongoing dialogue between providers and regulators with respect to quality monitoring (Braithwiate 1998), they have also transformed the context of practice in RACFs. Research has suggested that unrelenting documentation requirements associated with accreditation and funding, in addition to decreased staffing levels, have resulted in greater workloads and nursing staff reporting a sense of powerlessness (Jones et al. 2002) and professional dissatisfaction (Moyle et al. 2003; Ellis & Pompili 2002).

The perceived necessity to privilege documentation and administrative tasks, at the expense of providing holistic resident care, has been reported both within the Australian (Moyle et al. 2003; Venturato et al. 2007) and international literature (Bowers et al. 2001; Martin et al. 1999; Carr & Kazanowski 1994) as frustrating nursing staff’s efforts to practice with greater autonomy within long-term care environments. This situation is manifest in the reports of nursing staff that their day-to-day practice is focused on time management strategies, whereby care is organised around routines and is predominately task-orientated (Bowers et al. 2001). Lacking time and dealing with increasingly more complex resident care needs, nursing and care staff are reported as predominately practicing in a reactive (Allen et al. 2008) manner. PCAs report needing to improve supervision and guidance when caring for dying people (Miskella & Avis 1998) while nursing staff report an inability to manage administrative tasks, clinical work and supervision of unregulated workers (PCAs) (Ellis & Pompili 2002). In addition to these circumstances, regulatory
processes such as accreditation visits and spot checks have been identified by RACF staff as “highly stressful” (Robinson et al. 2007). In recognition of these tensions that shape the practices of RACF staff, Robinson et al. (2007) have described them as “living on the edge” with little capacity to support innovation and effectively respond to changing circumstances within their work environment. Given the trend of increasing resident dependency, these issues raise serious concerns about how aged care staff might provide a palliative approach to care that is espoused to be flexible, holistic and responsive to residents’ changing needs (ADoHA 2006).

The deskilling of the RAC workforce underpins a number of concerns about capacity of staff to deliver a palliative approach to care (Phillips et al. 2006; Strumpf et al. 2004) and meet the needs of the increasing number of people with dementia. As previously discussed, PCAs comprise the majority of the aged care workforce in Australia (Richardson & Martin 2004) and overseas (Chandler 2003), and provide almost all of the hands-on care to residents. In Australia, these staff have minimal and variable education, with 20% of the workforce having no training at all (Martin & King 2008, p.15). However, the provision of palliative care for an older, frailer resident population, in particular those people with dementia, has been identified by numerous authors as requiring highly skilled clinicians (Cooper & Mitchell 2006; Cooper & Glaetzer 2004; Venturato et al. 2006; Abbey et al. 2006; Joy et al. 2000).

As previously discussed in sections 2.2.3 and 2.3.3, there is evidence to suggest that PCAs and nurses require further education about dementia and palliative care. However, access to educational opportunities are reported as problematic due to short staffing and skill mix issues (Maddocks et al. 1996; Ellis & Pompili 2002). The availability of education appropriate to meet the needs of different staff in the aged care sector (Froggatt 2000a; Abbey et al. 2006; Whittaker et al. 2007) has also been identified as a barrier to knowledge development. An evaluation of a two-year palliative care education program across 54 nursing homes in the UK demonstrated that palliative care courses designed to meet the needs of different levels of staff in nursing homes had a positive impact on the understandings and practices of those who attended (Froggatt 2000b). However, to affect organisational change Froggatt (2000a) has suggested that collaboration with staff and other agencies that have an interest in the provision of palliative care in nursing homes is necessary. Collaborative approaches to improve knowledge, practice and promote wider organisational change are also emphasised as a mechanism to reduce the isolation of aged care staff.
2.5.2.2 Isolation of RACF staff and service fragmentation

The overall decrease in the numbers of RNs and ENs in the aged care workforce, increased work demands and greater numbers of unregulated PCAs have been identified as factors contributing to professional isolation of nursing staff in RACFs (Venturato et al. 2006; Jones et al. 2002). It has been reported that nursing staff in RACFs have limited opportunities to network with their professional colleagues, both within the RACF where they work and across other facilities and sectors (Jones & Cheek 2003; Venturato et al. 2006). The adverse impacts of institutional isolation of PCAs from nursing staff have been reported as reducing PCAs job satisfaction, as well as limiting the transfer of knowledge to these professionals that could inform and improve care provision (Venturato et al. 2006; Ersek et al. 2000; Ersek et al. 1999; Miskella & Avis 1998). Professional isolation is not an issue unique to Australia. Research in Ireland (Hasson et al. 2008), the UK (Froggatt & Hoult 2002; Komaromy et al. 2000) and the US (Avis et al. 1999) has identified that staff in long-term care environments have little professional interaction with colleagues outside of their own organisation and variable access to education that could facilitate the development of professional networks (Joy et al. 2000). These circumstances have been identified as restricting aged care staff from sharing experiences, accessing new information and developing further competence and confidence to implement evidence into practice (Carr & Kazanowski 1994).

Australian research (De Bellis & Parker 1998; Clare & De Bellis 1997; Grbich et al. 2005) has indicated that RACFs mainly utilise palliative care expertise or support from specialist services, via informal methods for the requisition of advice rather than comprising ongoing multi-disciplinary involvement. Similar findings have been reported in the UK (Froggatt et al. 2002, p.486). Aged care staff have reported desiring greater networking opportunities with colleagues from specialist and other multi-disciplinary services to enhance the delivery of palliative care to residents (Phillips et al. 2006; Komaromy et al. 2000). One method that has undergone investigation is the establishment of a palliative care “link nurse”, whereby a nurse with specialist qualifications, collaborates with RACF staff to support education, changes in practice and networking with the specialist area (Cotterell et al. 2007; Maddocks et al. 1996). However, external factors such as varying care needs of residents, lack of management support, and difficulty accessing GPs who are responsible for residents’ medical care are highlighted as challenging the
effectiveness of these roles (Whittaker et al. 2007; Froggatt & Hoult 2002; Hasson et al. 2008).

Other strategies found to be successful in reducing professional isolation of nursing and care staff and promoting professional development centre on the promotion of collaborative relationships. In a project that aimed to improve the support for undergraduate nursing students on clinical placement across six facilities, nurses and PCAs were provided with opportunities to meet regularly and collaborate with colleagues (Robinson et al. 2005a). Robinson et al. (2005a p.128) reported that this networking was crucial to “providing a key impetus for professional development”, and the implementation of strategies that supported best practice. Other studies have reported on the positive outcomes of action-oriented methods in fostering collaboration between nursing staff (Dewing & Traynor 2005) or aged care staff, family member and residents (Aveyard & Davies 2006) to promote change through regular dialogue and shared understandings. Drawing on similar ideas, Phillips et al. (2006) have emphasised the importance of supporting the unregulated workforce and enhancing opportunities for staff to network with other professionals through innovations such as the establishment of action learning groups. It is evident that further research is needed to investigate the impact of professional isolation on the implementation of a palliative approach to care in RACFs, as well as ways of overcoming barriers. While the present study offers this opportunity, it also creates possibilities for a more detailed understanding about the culture of care in RACFs and the challenges that this may present to the implementation of a palliative approach to care.

2.5.2.3 Cultural dissonance: the impact of competing agendas on palliative care practice in RACFs

The dissonance between the espoused values of person-centred, holistic care in RACFs and the dominant imperatives of economic rationalism that promotes task orientated, routinised care practices have been identified as a barrier to the implementation of palliative care (Angus & Nay 2003; Venturato et al. 2006; O'Connar & Pearson 2004a). Bowers, Lauring and Jackson (2001 p.490) interviewed 18 nurses from two long-term care settings in the US. Their findings revealed that aged care nurses prioritise their competing work demands based on what tasks they “must do” in order to meet system/regulatory imperatives and economic demands, rather than what they “should do” to fulfil the goals of holistic, person-centred care.
(Bowers et al. 2001). Bowers et al. (2001) recognised the ethical as well as legal implications of nurses’ complicity with organisational agendas that sought to maximise efficiency. They (Bowers et al. 2001, p.489) highlighted that time management strategies “such as medications being skipped...avoiding engagement with residents and families” has adverse outcomes on care providing and residents’ quality of life. Similar concerns have been raised by Tuckett (2005 p.220) in Australia, who suggested that “production line” care provided by PCAs in this setting characterises the culture of nursing homes that privileges instrumental care over individuals’ needs.

The literature suggests that a culture of reactive, task-oriented care is dominant in the RAC setting, and that nurses feel powerless to provide the holistic care to which they may aspire (Bowers et al. 2001; Jones et al. 2002). The implications of this culture include the likelihood that people such as RNs, who are also clinical leaders, have reduced opportunities to access evidence and be receptive to it use (Kitson, Harvey & McCormack 1998). Watson Hockley and Dewar (2006 p. 238) supported this contention, reporting that with increasing care complexity and administrative demands on aged care staff, attempts to implement an end-of-life pathway revealed what they considered to be a “lack of a learning culture”. These are important issues in the context of this study, because in the absence of a culture that promotes ongoing learning, staff are less likely to be motivated to accept change (McCormack et al. 2002).

Further reflective of the cultural concerns shaping care practices in RACFs, Jones, Cheek and Ballantyne (2002) have articulated that in Australia policies that emphasise a “restorative” or “rehabilitative” care culture have been dominant. Abbey (1994 p. 42) has contended that care has been shaped by principles of “normalisation”, which Maddocks and Parker (2001 p. 148) explain encourages “continued activity and rejects unnecessary limitation of function”. This philosophy was reflected in the funding tool for RACFs (the RCS), which according to Edwards and Forster (1998 p.8) focused on maximising independence and maintaining function. Abbey (1994 p.42) pointed out that a care culture that supports “normalisation” as a “raison d’être” failed to take account of the complex care needs of increasingly older and frail people in RACFs, including those with advanced dementia. Hence, the restorative care culture of RACFs exists in tension with a more recent emphasis on these settings as locations of palliative and end of life care
(O’Connor & Pearson 2004b; Phillips et al. 2006). Abbey (2006) argued that for too long death-averse cultures in health care organisations have “hampered learning”. Additionally, Angus and Nay (2003 p.131) contended that the propensity to “de-emphasise” the complex clinical needs of older people, reflected the dominance of economic rationalist interests across the sector. They (Angus & Nay 2003, p.136) have argued that marginalisation of nursing practice by way of its transformation to meet managerial/administrative interests, has been largely taken for granted as has the disjuncture between economic rationalism and holistic, responsive care. At the beginning of this study research exploring the impact of such cultural dissonance on the provision of a palliative approach to care for people with dementia was lacking. Hence, this project provided important opportunities to explicate the culture of care around dying and death in a RACF, and explore strategies to engage staff in action that could facilitate supportive culture change.

RAC is one of the most highly regulated sectors in the Australian health care system, and the implications of a culture of compliance on the development of evidence-based practice has been highlighted (Venturato et al. 2006). With the regulatory framework having been described by some aged care RNs as “punitive” (Venturato et al. 2007, p.9) and where “fear of bureaucratic reprimand and/or withdrawal of funding” influences how care practices are constructed (Angus & Nay 2003, p.134) arguably such conditions are not conducive to producing a context that is receptive to change and supportive of innovation. Braithwaite, Makkai and Braithwaite (2007 p.93) have argued that implications of the regulatory environment have driven a culture of “ritualism” in RACFs within Australia, the US and the UK. Reflective of the dominance of regulatory and institutional interests they have contended that aged care staff predominantly focus on the rituals that achieve certain outputs and satisfy regulatory requirements rather than on processes that actually impact on care outcomes and improve quality of care. Indeed, Braithwaite and colleagues (2007 p.82) called for coalitions between providers, regulators, advocates and researchers to shift from “ritualism to innovation”. While some research has been published about establishing collaborative partnerships between RACF staff and university researchers (McConnell et al. 2007) to facilitate evidence-based practice, strategies to develop wider coalitions, particularly with regulators, have received considerably less attention.
2.5.2.4 The implications of workforce hierarchy

Hierarchal workforce structures and autocratic decision-making processes in health care settings (McCormack et al. 2002) have been reported to fracture communication processes and thus undermine opportunities for the translation of evidence into practice (Dopson et al. 2002). Jervis’ (2002) ethnographic study investigated power relations between nursing assistants (PCAs) and nurses (RNs and Licensed Practical Nurses (LPNs) or ENs) in a US long-term care facility and exposed how communication occurred via a “chain of command”. He (Jervis 2002, p.14) explained that this finding revealed an organisational “trajectory of power”, within which care staff (PCAs) experienced the least autonomy, minimal impact on decision-making, and subordination within a clearly defined nursing hierarchy. Nursing staff were also reported as largely disconnected from care staff, with managerial and documentation demands meaning that they seldom worked alongside them (Jervis 2002). Similar organisational arrangements have been reported by Beck and colleagues (1999), suggesting a disengagement between staff members in RACFs. With the provision of a palliative approach (ADoHA 2004) to care being predicated on collaboration between staff members, such hierarchical power relations present a barrier to implementation. Rigid organisational structures have been reported to stifle information sharing and effective communication amongst team members (Jervis 2002), resulting in poor teamwork and an environment unconducive to change (Jervis 2002; McCormack et al. 2002; Dopson et al. 2002). For example, role demarcation has been reported to impede PCAs, who are at the frontline of care, from communicating with family of residents about end-of-life issues for fear of stepping into the domain of the nurse (Ersek et al. 2000, p.21). Ultimately, these circumstances fail to meet the needs of family caregivers for information and support with respect to end-of-life decision-making (Caron et al. 2005a).

There is a need to better understand how organisational hierarchies impact on the capacity of PCAs to support a palliative approach to care for people with dementia. It is evident from more recent research in Australia (Lyon 2007; Grieve 2006) that the effective implementation of evidence into practice requires leadership of management and a positive desire to promote change. The frequent turnover of RACF management, however, has been identified as a substantial barrier to the implementation of a palliative approach to care in RACFs (PCA 2007; Strumpf et al. 2004; ADoHA 2004; Dewling & Wright 2003).
2.5.2.5 Summary of key issues

The literature has identified numerous challenges to implementing a palliative approach to care for people with dementia in RAC. To summarise, the dominance of economic rationalist agendas within the aged care environment (Angus & Nay 2003), manifest in the changing workforce structure (Chandler et al. 2005) and increased administrative burdens on nurses (Venturato et al. 2007), have failed to adequately account for the complex needs of older people (Angus & Nay 2003; Venturato et al. 2007). The compliance of staff with rehabilitative (Jones et al. 2002; Abbey 1994; Abbey et al. 2006) and task-oriented (Bowers et al., 2001) care cultures supports a “production line” (Tuckett 2005, p.220) model of care in RACFs that undermines the provision of holistic resident care and reinforces the silence that prevails around death and dying in this setting (O'Connor & Pearson 2004a; Komaromy 2000). These circumstances can deny aged care staff opportunities to critically reflect on their practices, access evidence and challenge their habitual ways of working (Watson et al., 2006). The implications of these circumstances are further manifest in the isolation of staff members from each other (Jones et al. 2002; Avis et al. 1999; Miskella & Avis 1998), and hierarchal power relations (Jervis, 2002) that undermine opportunities for collaboration and development of learning cultures that could support innovation. Hence, aged care staff experience a sense of powerlessness to change their practices (Moyle et al. 2003; Jones et al. 2002). Inevitably, these problems culminate in deleterious and unjust consequences for people in the most vulnerable positions in RACFs – those with dementia and their family caregivers. Research continues to reveal (see section 2.3.3) the sub-optimal provision of palliative care. Undoubtedly, there is an imperative to investigate strategies that will enhance the capacity of the RAC sector to engage with an evidence-based palliative approach to care that is proactive, responsive and holistic.

2.6 A way forward

The aged care sector has and continues to be as Abbey (2006) has highlighted “a system in change” and this presents numerous challenges to developing practices around an evidence-based palliative approach to care. Ensuring that RACF staff are appropriately prepared to meet the needs of frail older people is paramount. In particular, the need is pressing for people with dementia in long-term care settings who continue to be referred to as the “disadvantaged dying” (Robinson et al. 2005b). Their inequitable access to a palliative approach to care may cause needless suffering.
and distress for them, their families and those providing care. However, there are markers of hope within the literature that demonstrate the potential for improvement. It is evident that collaborative and action-oriented approaches are increasingly being adopted and recognised as supporting the development of evidence-based practice in RACFs (Nolan et al. 2007b). Froggatt et al. (2006) has highlighted the need for development work “looking beyond the current research methodologies”. Consistent with Froggatt and colleagues (2006), Hockley (2002, p. 177) has advocated the use of action research methods to “enhance knowledge and practice of palliative care for older people dying in nursing homes”.

The importance of addressing contextual factors in order to facilitate RAC staff to provide an evidence-based palliative approach to care is crucial (Froggatt 2001b; Phillips et al. 2006). Action research approaches, situated in a critical social science paradigm have been promoted within the practice development literature (McCormack & Garbett 2003; McCormack et al. 1999; Tolson et al. 2006) as methodologies capable of transforming culture, context and practice. Manely and McCormack (2003, p. 25) have explained that critical social science can be used to collaborate with people, such as aged care staff, to reflect on their practice, recognise contradictions and associated issues of power and inequity, and illuminate directions for action with a view to improvement. A resounding message woven through the literature is the imperative to work “with” aged care staff (Watson et al. 2006, p. 239) and other key stakeholders to generate knowledge and integrate evidence into practice. This imperative motivated the decision to employ a critical action research approach, which is the focus of the next chapter.
Chapter 3: Theoretical and Methodological Foundations

This study employed a critical action research method to investigate the possibilities for developing the practices of staff working on a dementia SCU around a palliative approach to care (ADoHA 2006). Underpinned by critical theory, action research provides opportunities for practitioners, such as aged care staff, who have a desire to improve care provision, to work in partnership to develop critical and self-critical understandings of their situation (Kemmis 2001, p.96). Because critical action research supports both individual and collective aspirations for change (Mattsson & Kemmis 2007) it was the preferred method in this study to support SCU staff to engage in processes where they could develop their practice in ways that would support a palliative approach to care.

The first section of this chapter addresses the central theoretical tenets of critical theory. Following this, the key interests of critical theory, including concepts of hegemony and ideology are explored, as well as the role of taken-for-granted understandings in supporting hegemonic power relations. Habermas’ (1972, 1984, 1987a) theories of “knowledge-constitutive interests” and “communicative action” are then explored, as these works have been pivotal in advancing critical theory and are directly relevant to a project that seeks to dialogically engage RACF staff to examine their practices. Strategies such as storytelling, critical reflection and collaboration that will support SCU staff members to engage in a critical endeavour are examined, prior to an analysis of the concepts of enlightenment, empowerment and emancipation. A discussion of the challenges and contributions posed by post-modernism to the critical research endeavour concludes the first section of the chapter.

Section two examines the action research approach; its historical developments and the relevance of Habermas’ (1972) knowledge constitutive interests to the typologies of action research. Considerations of the practicalities of conducting critical action research with staff members from the SCU and monitoring processes of change are then explored.

3.1 Critical theory – an introduction

Critical theory has its roots in a diversity of positions that originated in the Frankfurt Institute for Social Research (Kincheloe & McLaren 2008; Giroux 1983; Carr &
Kemmis, 1986). During the 1930s the Institute came under the leadership of Max Horkheimer and other influential theorists such as Theodor Adorno and Herbert Marcuse became members of the school (Giroux 1983). There was a prevailing belief amongst these critical theorists that “injustice and subjugation shaped the lived world” (Kincheloe & McLaren 2003, p.434) and as such there was a crucial need to revisit the meanings of domination and emancipation (Giroux 1983).

Of particular concern to the Frankfurt theorists was the growth of instrumental rationality in the West and the tendency within society to reduce practical problems to technical issues (Carr & Kemmis 1986). Accordingly, they argued that rationality had become defined in terms of conformity to a set of rules related to scientific-reductionist thinking, whereby the capacity of humans to critically reflect on their situation and change it through their own actions was silenced (Carr & Kemmis 1986, p.133). The Frankfurt theorists shared aspirations to free people from “positivistic domination of thought” (Giroux 1983, p.130). They believed that orthodox Marxism had failed to fully recognise the benefits of self-criticism as a means of exposing “taken for granted” understandings that supported ideological interests (Held 1980; Giroux 1983). Here, ideology can be understood as the promulgation of a “highly articulated worldview” (Kincheloe & McLaren 2008, p.330) that promotes, justifies and masks dominant interests. The work of “second generation” critical theorist, Jürgen Habermas (1972, 1973, 1979, 1984, 1987a) advanced critical theory in a number of crucial directions, thus furthering its methodological utility. Reinvigorating Aristotelian notions of praxis and social reason (Carr & Kemmis 1986; Giroux 1983), Habermas stressed the importance of self-reflection, critique, communicative freedom and critically informed action (praxis) as a means to expose dominant ideology to redress injustice in society.

By unmasking sources of domination and oppression, critical theory seeks to challenge and disrupt dominant power relations and cultivate an emancipatory agenda (Rush 2004, p.9). Accordingly, critical theory has underpinned a variety of approaches such as black liberation research (Edmondson Bell 2001), action research (Street 1995, 2003; Carr & Kemmis 1986; Grundy 1988; Fals Borda 2001), critical pedagogy (Freire 1970) and feminism (Gore 1992, 1993; Lather 1991). Common to all of these approaches is that they seek to engage subordinate, previously silenced groups of people, to, as described by Kincheloe and McLaren (2008 p.407), “irritate dominant forms of power”, with the goal of increasing social justice. Thus, Rush
(2004 p.9) has explained that critical theory does more than simply criticise and for this reason is not “merely descriptive” but:

...is a way to instigate social change by providing knowledge of the forces of social inequality, that can, in turn, inform political action aimed at emancipation (or at least at diminishing domination and inequality).

While there is not one unifying definition of critical theory there are conceptual commonalities that broadly underpin the “critical tradition” (Kincheloe & McLaren, 2003 p.404).

### 3.2 Concepts central to critical theory

Concepts germane to critical theory are hegemony, ideology and taken-for-granted understandings. Given that a central interest of critical theory is to expose and disrupt dominant power relations, it is pertinent to consider the ways that hegemony, ideology and taken-for-granted understandings operate to sustain oppressive circumstances.

#### 3.2.1 Hegemony, ideology and taken-for-granted understandings

Ideology is the promulgation of ideas that support, rationalise and mask dominant interests in civil and political society (Giddens 2006; Kincheloe & McLaren 2008). Gramsci (1971), a Marxist scholar, furthered this view and argued that ideology shapes peoples’ consciousness and gives particular orientations for action. Hence, through ideology people can come to see their position in the world as natural and inevitable (Kavanagh 1990; Kincheloe & McLaren 2008). Gramsci (1971 p.327) wrote extensively about hegemony, describing it as the ability of a dominant group to secure the consent and adhesion of the masses through “spontaneous consent”. He (Gramsci, 1971 p.268) wrote that people consent unknowingly to domination and the institutionalisation of inequity in society, arguing:

> the individual can govern himself without his self-government thereby entering into conflict with political society but rather becoming its normal continuation, its organic complement.

Not dissimilarly to Gramsci, Chomsky (2003 p.6) a linguist and political writer, referred to “the manufacture of consent” as the means by which the opinions and attitudes of people could be controlled through what appears as ordinary, everyday knowledge. Evident in the work of both Gramsci and Chomsky is the
acknowledgement that repressive force is of little strategic efficacy to secure hegemony, and thus peoples’ unwitting consent to domination. Rather, Gramsci (1971, p.420) explained that it was through “common-sense” knowledge that “spontaneous consent” could be achieved. Common-sense is largely invisible to the individual because it is reinforced through day-to-day familiar experiences and practices of institutions in “civil society” such as schools, churches, museums and media (Gramsci 1971, p.110). Under these conditions, cultural practices and rituals operate to promote conformity with dominant ideological interpretations of the world (Crotty, 1998, p.143). Thus hegemony is a “situationally specific” form of domination that shapes how people view their reality (Kincheloe & McLaren 2008, p.412). Gramsci (1971) has asserted that hegemony is articulated through “capillary power” whereby common-sense understandings and attitudes go unexamined because they appear as natural and familiar. Accordingly, the “validity” of ideology is sustained in peoples’ consciousness through common-sense (Gramsci 1971, pp.376-377). By people adhering to or not challenging common-sense, they provide “active or passive assistance” (Gramsci 1971, p.53) in sustaining hegemonic power relations. Under such conditions, Comstock (1982 p.374) has argued that people’s understandings are “historically frozen by ideologies which legitimate and attempt to perpetuate existing relations of power”. A key interest of critical theory is thus to expose the operation of power relations by revealing how common-sense understandings arise from and mask dominant interests.

The implications for aged care staff working on a SCU to “confront commonsense” that “defines [their] daily existence” (Bauman 1976, p.74) are of key importance to this project. Within the aged care environment, the operation of hierarchical power relations amongst different staff (e.g. RNs, ENs, PCAs, GPs) (Jervis 2002) and between staff and family members (Bauer 2006) is largely a taken-for-granted feature of the setting. Thus, hierarchical relations frame the ways that these stakeholders engage with each other. For example, evidence indicates that the knowledge possessed by nursing staff, based in medical-technical agendas, is privileged in the aged care setting as more valid and reliable than for example, family caregivers’ knowledge of residents that is based in local, biographical and personal experience (Bauer 2006; Kellett 1998). As long as people unwittingly consent to sustaining these relations, hegemonic agendas can likewise be sustained.
Language plays a central role in shaping hegemonic agendas and therefore is of key interest in this project. Kincheloe and McLaren (2008 p.412) have argued that language not only describes, but serves to construct the world. When language is arranged in a way that regulates and dominates “what can and cannot be said, who can speak with the blessing of authority and who must listen”, it can be understood as forms of “discourse” linked to social contexts and power relations (Kincheloe & McLaren 2008, p.412). Kincheloe and McLaren (2008, p.413) have referred to “power discourses” as types of knowledge formed by dominant groups that undermine alternative understandings and meanings not consistent with the group’s ideological interests. Hence, discursive practices can be used to disguise hegemonic power relations and promote the status quo (Kincheloe & McLaren 2008; Gaventa & Cornwell 2001). The post-structuralist writer Foucault (1980a, p.52) conceived of power and knowledge as “integrated with one another” such that one directly implies the other, to produce what he has referred to as “regimes of truth” that support dominant interests. In this sense, within institutions such as RACFs certain “truths” may be adopted by staff that give particular orientations for action, with little critical attention. For example, the construction of care practices around a rehabilitative/restorative ethos of care (Abbey 1994; O'Connor & Pearson 2004a; Abbey et al. 2006) in RACFs reflects dominant cultural and economic imperatives of these settings. It could be argued that the regimes of truth which give rise to these staff practices and understandings fail to account of the increasingly complex needs of older people entering RACFs, in particular those with dementia. This is a concern that has emerged within the literature (Abbey et al. 2006).

Within institutions such as RACFs, hegemonic power relations can be understood as existing in what Kincheloe and McLaren (2008, p.412) have described as a “context of concurrent struggles” between groups with differing interests. Being subject to contestation these relations are at best partial and uncertain (Kincheloe & McLaren 2008). One type of contestation that has been reported in RACFs (Jervis, 2002) is what Scott (1990, p.190) has referred to as “everyday forms of resistance”, these being subtle, low profile acts that have a reduced risk of retribution but can provide a feeling of empowerment for those who deploy them. Jervis (2002) has explained that within the RAC setting where PCAs have little autonomy and are subordinate to nursing staff, they may covertly undertake activities that will negatively impact on organisational functioning or the dominance of nursing orders. While such practices are not commensurate with the development of evidence-based practice or overall
quality of resident care, it is this ability of people to exercise a measure of power to
counter what they consider to be unjust circumstances that renders hegemonic power
relations as provisional and vulnerable to disruption. Habermas, a second generation
critical theorist, advocated that dominant power relations could be exposed by
gaining insights into how knowledge is constructed through communicative
practices.

3.3 The relevance of knowledge-constitutive interests

Habermas (1970) argued that communication is “systematically distorted” when
genuine consensus cannot be achieved due to regulation, repression or censorship by
dominant groups. He (Habermas, 1972) asserted that to expose sources of distortion
emancipatory knowledge must be produced. Central to the production of this
knowledge is the process of critique in unmasking taken-for-granted understandings.
Habermas (1973) maintained that by engaging in self-reflection individuals can
emancipate themselves from dependencies that had previously gone unrecognised.
Through the “Theory of Knowledge-Constutive Interests” Habermas (1972)
analysed knowledge production to demonstrate the connection between knowledge
and human activity. Through this analysis technical-instrumental knowledge is
described as not value free but motivated by human needs and interests (Habermas,
1972). Habermas (1972, 1974) presented three types of interests: technical, practical
and emancipatory, which he asserted took form in work, language and power
respectively. These interests that shape knowledge are referred to as “a priori”, as
they arise from cognitive processes that are embedded within life structures
(Habermas 1972, pp.211-212). Therefore, knowledge production is inextricably
linked with social practice (Fay 1987, p. 102).

According to Habermas (1972, p. 191) technical interests involved “the production
of technically exploitable knowledge”, where reality is disclosed “from the viewpoint
of possible technical control over objective processes”. Habermas does not reject
technical knowledge as a legitimate source of knowing. However, he (Habermas
1972) has asserted that reality understood solely under these circumstances “has its
counterpart in a specifically restricted mode of experience” (p.191), where it is
objectified and “language is separated out of its embeddedness in interactions and
attains monologic closure” (p.193). As such, the unique experience of individuals is
largely eliminated, in favour of work that is grounded in “purposive-rational means”
that produce results that are repeatable and controllable (Habermas 1972 p.193).
With the domination of technical interests, Habermas (1987b) has contended that there is a propensity to identify problems within social life in terms of technical issues, which inevitably supports a particular class interest in domination.

*Language*, according to Habermas (1972 p.192) “establishes schemata of world interpretation and interaction” and is constitutive of the social world. Knowledge developed within interpretative frameworks is based on **practical interests** and is orientated towards mutual understanding (and self-understanding) through intersubjectivity and “tradition bound symbolic interaction” (Habermas 1972 p.191). This knowledge, situated in the domain of hermeneutics (Habermas 1972 p.191), in the form of interpretive understanding, is not reducible to technical or scientific reason. Habermas (1972 p.192) attested that it was possible only to develop such knowledge “as socialized participants and not as impartial observers” of the world. However, the lack of critical questioning within the interpretive paradigm undermines any realisation of how forms of social interaction and communication may be distorted by dominant ideological interests. Habermas (1972, 1973, 1974) argued that knowledge based in practical interests did not take account of the fact that language could be used as a means of domination. Thus, both technical and practical knowledge can produce action which serves to support and protect existing structures of domination within society. Further, Habermas (1972) has argued that neither type of reason is sufficient to develop a comprehensive explanation of society; thus he arrives at emancipatory interests.

**Emancipatory interests** are orientated towards the investigation of ideology and power within society. Habermas (1972) elaborated that emancipatory knowledge served human interests in autonomy, responsibility and freedom. It is through the production of such knowledge that people gain insights into relationships of power and ideological domination and the means by which language can disguise these relationships within a given setting (Habermas 1974, pp.39,253). Outhwaite (1994, p.34), in his examination of Habermas’ work, pointed out that emancipation is envisaged as “leaving behind the sources of distortion” with the re-construction of a more conscious self, which in turn, relied on “self reflection” and “critique”. The generation of critically reflective knowledge, according to Comstock (1982, p.375), reveals the “contradictory consequences” for people’s autonomy and freedom that result when they act in accordance with ideology that supports dominant and usually hierarchical interpretations of the world.
Critical research methodologies, such as critical action research, aim to generate emancipatory knowledge through critique of everyday life, and in the process disrupt forms of domination and repression that sustain inequitable circumstances (Giroux 1983, p.130). By employing a critical methodology, SCU staff in this project had an opportunity to reflect on how their palliative care practices were shaped by taken-for-granted understandings that support hegemonic power relations. As Street (1992 pp.74-75) suggested with respect to clinical nursing, this type of examination may assist people to recognise how their conformity to “institutional rules and routines” permits complicity in their own oppression. According to Habermas (1984), this type of critical examination required collaborative, communicative acts, through which people could come to an agreement about sources of distorted communication that masked hegemonic power relations. The next section explores theories developed by Habermas around the centrality of language and communication (or dialogue) in exposing the sources of oppression in social settings.

3.4 The centrality of language and communication in exposing hegemony

3.4.1 Communicative competence

In Habermas’ (1979) “Theory of Communicative Competence”, he argued that emancipatory potential was embedded within the very structure of language and the conditions under which speech acts occur. Habermas (1974, p.19) asserted that people could only come to an understanding of their situation that was not tainted by forces of coercion and manipulation, through an “ideal speech situation”. The ideal speech situation presupposes that all people have an equal opportunity to speak and can engage in unconstrained dialogue. Additionally, Habermas (1984, p.307) has asserted that “speech acts” aimed at mutual understanding and consensual agreement are necessary for individuals to uncover taken-for-granted understandings of their world. Accordingly, these “speech acts” must satisfy four “validity claims”, these being: “comprehensibility”, “truth”, “correctness” (to the context) and “sincerity” (Habermas 1984, pp.38-41). Habermas (1973, p.168) has argued that it is through “discourse” framed by an ideal speech situation that validity claims of statements or opinions can be examined. Here, discourse can be understood as rational argument through which people can test whether what is said about a particular situation is true, comprehensible, sincere and correct.
Habermas (1979) argued that communication which was distorted by the interests of others becomes noticeable when utterances could not satisfy the aforementioned validity claims. Accordingly, Kemmis (2001, p.96) has highlighted that Habermas’ validity claims provide a foundation for critical reflection. Drawing on Habermas’ work, Kemmis (2001, p.96) has offered the following four questions that can be used to examine the validity of any utterance: “Is this utterance comprehensible?, Is it true [in the sense of accurate]?, Is is right and morally appropriate? [and] Is it sincerely or truthfully stated?”

Similarly Outhwaite (1994, p.40) has illustrated the practical application of validity claims when framed as questions that can guide discourse: He states: “Thus we can ask a speaker for example ‘‘what do you mean?’’, ‘is what you say true’, ‘are you entitled to say that?’”, “Do you really mean it?’”

Taken from this perspective, dialogic engagement may provide opportunities for aged care staff in this study to critically examine what they previously considered to be ‘true’ and uncover how their understandings and practices have been shaped by taken-for-granted assumptions that support hegemonic power relations (Kemmis 2001, p.96). Drawing on Habermas’ work, Park (2001, p.89) has highlighted that critically reflective knowledge takes into account questions of morality and values related to everyday life. Therefore, through ‘discourse’, which from a Habermasian perspective refers to rational argument that is aimed at reaching agreement, understandings of a particular situation can be reconstructed to be more socially just, so that people can come to act with “greater degrees of autonomy and human agency” (Kincheloe & McLaren 2008, p.409). Accordingly, the centrality of dialogue to emancipatory aspirations is evident in Habermas’ work.

Chambers (2004, p.234) has pointed out that critiques directed at Habermas’ “ideal speech situation” and the fulfilment of validity claims identify these notions as idealistic and utopian. A number of critical scholars observe that few discussions truly correspond to open and free communication, however, they also point out that Habermas himself recognised this (White 2004b; Carr & Kemmis 1986; Outhwaite 1994). Rather, it is the “possibility” (Outhwaite 1994, p.40) of ideal speech that is important because the conditions for its accomplishment set up circumstances for democratic discussion (Carr & Kemmis 1986). In the case of this study, a critical methodology provided an opportunity for SCU staff to engage openly and
democratically in discussions about developing a palliative approach to care provision.

3.4.2 Communicative action

Speech acts aimed at satisfying validity claims can be understood as a way of setting up democratic, dialogic, critically reflective encounters that have illocutionary effects. Outhwaite (1994, p.46) has explained that an illocutionary act “does something in the act of saying something”. Habermas (1984) in his “Theory of Communicative Action” has argued that speech acts pursue “illocutionary aims” (p. 294) by arriving at an unforced, mutual understanding about a situation that then provides a basis for “harmonising plans of action” (p.286). Habermas (1984, 1987a) has referred to this as communicative action and has explained that it finds expression in the “lifeworld”.

In his theory “Theory of System and Lifeworld”, Habermas (1987a, p.118) emphasised that we should “conceive of society simultaneously as systems and lifeworlds”. Habermas’ (1987a, p.125) has explained that “language and culture are constitutive of the lifeworld”, whereby people reach mutual understandings about a situation from a “stock” of knowledge that is “always already familiar” and taken-for-granted. Drawing on Habermas’ work, Kemmis (2001) has explained that from a system perspective, social life is founded in rational-purposive action. This is, action orientated towards attaining specific types of outcomes, linked to the way that the system functions; thus the system perspective relies on functional reason (Kemmis 2001). In the system world consensus decision-making is strategically bypassed or subordinated to reason oriented towards system goals of success (Habermas 1987a, pp.182-183). Hence, as staff members in this study engage in communicative action they may come to understand how their practices reflect taken-for-granted lifeworld and system world imperatives. Herein, they may come to recognise how aspirations, reflective of lifeworld processes (such as the development to shred meaningful relationships) that are supportive of a palliative approach are taken-for-granted and subordinated to system imperatives, directed towards efficiency and operationalised through functional, task-oriented care practices. Habermas (1974, p.22) has referred to action that emerges from such critically reflective dialogue as “praxis”.

The interrelationship between theory and practice is achieved through praxis; whereby critical reflection opens up possibilities for a critique of ideology and
challenges hegemonic structures as means to foster the development of emancipatory knowledge. In turn, this provides an impetus for people to take action (as praxis) to re-establish more equitable circumstances (Habermas 1974, pp.253-254). In Habermas’ (1996) later work, Between Facts and Norms, he introduced the concept of a “communicative space”. Referring to this work, Kemmis (2001, p.103) has argued that opening a communicative space is a third feature of communicative action, where people come together in discussion around issues of mutual concern which can create opportunities for praxis. Therefore, in this study aged care staff who may be professionally isolated from each other, through the operation of hegemonic power relations will have an opportunity to share their experiences of caring for people with dementia. The opening of such a dialogic space brings to the fore the importance of strategies such as storytelling and the construction of narrative, that will enable people to tell of their experiences in ways that are “accessible and meaningful” to themself and to others (Arvay 2002, p.114). In this project, storytelling was employed as a mechanism to provoke critical dialogue between SCU staff members.

3.4.3 Story-telling - a strategy to foster critical dialogue

Bleakley (2005) has suggested that people share their experiences through stories, as this brings ‘temporal order’ to what may otherwise be chaotic events in people’s lives. According to Aranda and Street (2001), stories are always framed historically and temporally, which enables people to make sense of happenings in their world. Similarly, White (1995, p.13), in his post-structuralist writings, has explained that stories are contextually bound as they provide a “frame of intelligibility” that allows people to attribute meaning to their experiences within a given context. In telling stories, people determine what particular aspects of their life they will “select for expression” (White 1992a, p.123) and from this perspective, stories do not merely “mirror” life, but rather, people live their lives through stories and hence “stories are shaping of life...have real, not imagined effects [and]...provide a structure for life”. The use of storytelling in this project offers an opportunity for aged care staff from the SCU to share their experiences and make sense of unfolding events in their practice worlds.

Crucial to the utility of story-telling in critical methodologies is the understanding that stories, by their very nature, are indeterminate. Stories have degrees of ambiguity, uncertainty and elements of contradiction (White 1992b, 1995). The teller
of the story and the listener have different ways of interpreting what is said or written based in their lived experiences. Hence, when a person hears a story from another, they can make sense of it by comparing it to their own experiences and background, and according to Koch and Kralick (2006, p.9) “a fusion occurs”, where as a hearer “I shape the story and I am shaped by it”. The collaborative processes of recounting, reconstruction and reflection through storytelling produces narrative accounts (Aranda & Street 2001, p.796). The “performative aspect” of story-telling, being “...the way story is told and heard”, permits the construction of narratives as a site for “contestation” and “clarification” between tellers and hearers (Aranda & Street 2001, p.792). This process has synergies with Habermas’ (1979, 1984) theoretical constructions of communicative competence, in which people challenge the validity of what is being said.

In the context of a critical endeavour, storytelling offers a way of provoking people to reflect on their experiences and frames of reference that they use to make sense of experiences (Aranda & Street 2001). This process opens up possibilities for people to dialogically “map the effects” or the consequences of problems, ambiguities or contradictions in their world (White 1995, p.23), thus challenging the validity of previously unexamined ways of seeing the world. This “deconstructive” feature of story-telling opens up possibilities for the production of narrative that can have a transformative function (White 1992b, 1995, 2004a). As stories are shared, an emerging narrative account can become a source of reflection (Aranda & Street 2001), in turn opening up possibilities for people to expose taken-for-granted understandings and recognise their personal implication in unjust situations. Through this ongoing process of critical reflection, hegemonic power relations that privilege the interests of one group over others can be exposed (Kincheloe & McLaren 2003), providing opportunities for people to gain insights into their ability to act differently to improve their situation. These dialogic processes resonate with what Outhwaite (1994, p.33) has referred to as Habermas’ “reconstructive” Theory of Communicative Action, where people continually examine the validity of what is and through defining and redefining their understandings, can arrive at a consensus that can lead to transformative action possibilities. According to Aranda and Street (2001, p.792), as people tell their stories and arrive at shared understandings, the ownership of narratives shifts from ‘mine’ to ‘ours’. However, this joint ownership of narratives between people necessitates the development of collaborative relations (Aranda & Street 2001).
3.4.4 Collaboration and reciprocity

Given that critical theory is concerned with countering hegemonic power relations by mobilising people who have previously been silenced and oppressed, collaboration is of central interest to critical endeavours. According to Winter (1989, p.56), collaboration can open up opportunities for multiple voices to be heard and a range of perspectives debated. As noted above, collaboration opens up opportunities for “co-authorship” of narratives in which people can come to see their situation “anew” (Aranda & Street 2001, p.792). Crucial to promoting a change agenda, collaboration is understood as mobilising a diversity of viewpoints (Koch & Kralik 2006).

Greenwood and Levin (1998 p.12) have asserted that through the consideration of numerous perspectives, groups of people and organisations have a “much greater capacity” for transformation.

Drawing on the work of Habermas (1984), Baynes (2003, p.202) has highlighted that communicative action is predicated on collaboration. Critically reflective knowledge, that is change-producing, emerges from group deliberation (Park 2001, p.89) and requires an “active” engagement with others as “co-deliberators” (Baynes 2003, p.202) to examine the validity of what is being suggested about a particular situation. Hence, conducting critical research “with” people, rather than “on” people takes account of their expertise and knowledge relevant to the specific context of the problem to be addressed (Heron & Reason 2001; Winter 1996). Moreover, the collaborative imperative of critical endeavours recognises that people have a right to be involved in decision-making and the development of knowledge that is about them and affects them (Reason & Bradbury 2001c, p.10). Therefore, people such as aged care staff are valued as “active agents” (Heron & Reason 2001, pp.144-5) in the construction of knowledge rather than passive recipients.

In view of the above perspectives, collaboration sets up opportunities for the establishment of more egalitarian and reciprocal relationships between people (Winter 1996), similar to what Habermas has promoted in his ideal speech situation. A collaborative approach can provide opportunities for SCU staff in this project to participate in discussions that have historically been constructed around hierarchical relations of the setting. Thus reciprocity supports democratic engagement. Lather (1991, p.57) explained that reciprocity in collaborative endeavours involves a “give and take” where a mutual negotiation of meaning through the sharing of stories creates opportunities for “collaborative theorizing”. Returning to the perspectives of
Aranda and Street (2001), reciprocity in storytelling may produce increasingly sophisticated narratives that in the context of a critical project can give voice to the complexity of practice and the competing interests that shape it. Through reciprocal, collaborative dialogic interactions “group solidarities can form” (Young 1997, p.92), which may facilitate mutual understandings and consciousness raising that has an empowering potential.

3.5 Enlightenment, empowerment and emancipation

At the heart of critical theory are the concepts of enlightenment, empowerment and emancipation. Habermas (1974, p.32) referred to the “organisation of enlightenment” whereby, people come to understand sources of distortion and irrational circumstances in their world. He (Habermas, 1974) claimed that the path to enlightenment was through processes of self-reflection and rational dialogue through which people could discover how their taken-for-granted assumptions have contributed to historically and socially constructed practices. Opening a communicative space where people can reflect on their situation free from coercion, creates opportunities for raising people’s “critical consciousness” to reveal “the particular and concrete ways” that they “unwittingly collaborate” in producing their own subjugation (Fay 1987, p.113). Habermas (1979) referred to this process as “rational reconstruction”, whereby people develop knowledge capable of exposing the subterfuge of hegemony.

Gaventa and Cornwall (2001, p.73) argued that as people developed critical insights into to the factors that constrained their actions, their understandings of their “capacities for action” could also be transformed. Barrett (2001) pointed out that for people to take empowered action to emancipate themselves from oppressive conditions, they must realise that they have a capacity to exercise power to “challenge the status quo and implement change”. Drawing on the work of Fox (1988), Lather (1991, p.4) has explained that empowerment is something one must do for oneself, not for others, as it “involves people coming into a sense of their power”. Yet Gaventa and Cornwall (2001, p.73), drawing on post-structuralist notions of power, have argued that people are at the same time “relatively powerful” and “relatively powerless”. This understanding emerges from Foucault’s (1977b, p.89) conception of power not as held but “exercised”, and thus only existing “in action”. Taken from this perspective, no person is exempt from power (Gaventa &
Cornwell 2001) and hence, empowerment relies on a reconfiguring of dominant power relations.

Freire (1970 pp. 42-43, 62) argued that this reconfiguration necessitates working in “communion” with people as “co-investigators” of their oppressive realities. He (Freire, 1970, p.62) argued that together people can participate in “critical and liberating dialogue” to generate emancipatory knowledge, from which action emerges. Freire (1907, p.69) has highlighted that when action is not critically informed it results in “activism” that threatens to perpetuate existing sources of oppression and injustice. In this study, the relationship between action and reflection will be a crucial indicator of the emerging empowerment. For SCU staff members, the opportunity to engage in critically reflective action will represent a radically different way of thinking and practicing, given that RACFs are historically reactive environments. The adoption of a shared positionality by people as workers and coresearchers is both reflective of a sense of empowerment and an empowering process itself (Barrett 2001). It is evident in the work of Friedman (2001, p.132) that the creation of “communities of inquiry within communities of practice” can galvanise the desires of likeminded people to engage in ongoing reflection and action from which emerges an increasing sense of ownership over the problems encountered and empowerment to redress dominant power relations. However, Kemmis (1996, p.230) has argued that there is no “universal vision” of what emancipation should look like within critical endeavours; at any moment it is possible for people to imagine what a better existence would resemble.

Moreover, McTaggart (1996, p.230) argued that “there is too much baggage associated with emancipation” and consequently it has been conceived by some that absolute revolution is necessary to achieve emancipatory ends. Contesting the assumption that emancipation is some “ideal state”, McTaggart (1996, p.245) has offered a more measured response, arguing that emancipation can be better understood by asking “regularly whether things are a little more rational (or reasonable), coherent, just, humane and satisfying for participants and others than they were”. For staff members working in the SCU, a critical approach may open up possibilities to develop proactive, empowered positions that will facilitate them to develop practices that would support a palliative approach to care.
3.6 Critical research and post-modern considerations

Having considered the theoretical concepts underpinning critical research, this chapter has presented predominantly modernist perspectives. This section will briefly address some of the key post-modern criticisms of critical theory and through this discussion consideration will be given to the contribution that post-modern thought offers within critical research approaches.

Numerous scholars (Mouffe 2000; Lather 1991; Lyotard 1984; Derrida 1981) have suggested that people are living in a new era of post-modernity that has had a profound effect on how they understand and experience their world. The work of Habermas and other earlier critical theorists is located within modernist thought (Crotty 1998). Post-modern considerations and criticisms of critical theory present numerous challenges to critical research endeavours. Critical theory has its roots in rationality, where instrumental reason is considered to dominate social life (Scott, 2006; Crotty, 1998). Modernity claims a path to enlightenment posited in the values of autonomy and the ability of reason to uncover absolute knowledge and the presence of “the truth” (Crotty 1998, p.185). Hence, notions of enlightenment such as those espoused by Habermas (1972, 1974) presuppose that there is a “truth” to be enlightened about. Encompassing a variety of positions (e.g. post-structural, post-industrial, post-colonial), post-modernism rejects “grand narratives” (Lather 1991, p.5) and replaces these with “an awareness of the complexity, contingency and fragility of historical forms and events” (Smart 1983, in Lather 1991, p.6). According to Crotty (1994 p.185) “postmodernism commits itself to ambiguity, relativity, fragmentation, particularity and discontinuity”. The very notion of truth in post-modern thought is therefore subject to intense scepticism. Bove (1990 p.55) explains that “truth” is made by humans as a result of very “specific material process” with respect to the authoritative discourse from which it arises. Within the post-modern, knowledge claims are always contextual and contingent, based on power/knowledge relations of certain discourses (Jennings & Graham, 1996 pp. 168,170).

The profound uncertainty of knowledge production and resultant action places notions of empowerment as problematic. Post-modern theorists argue that critical research serves to recreate and perpetuate the relations of power and oppression, with attempts to empower having inconsistent effects (Gore 1992). Gore (1993, p.121) has referred to this problem as the “repressive potential” of empowerment. Drawing on Foucault’s conception of power, Gore (1992, p.59) has argued that empowerment
can be understood as “the exercise of power in an attempt (that might not be successful) to help others exercise power”. However, there is a risk that the aim to empower paradoxically further disempowers people through the imposition of ideological assumptions. Thus, attempts of researchers to empower resulting in contradictory outcomes to their aims, have long been an abiding concern of feminist researchers (Maguire 2001). From a post-modern perspective, notions of empowerment may end up being rhetorical as there remains a distinction between those who aim to empower and those who are to be empowered (Gore 1992; Maguire 2001). Therefore, post-modernists argue that empowerment and emancipation should be understood as only ever being partial and contingent as they risk being undermined by the very process that aims to engender these outcomes.

In response to critiques of critical theory and critical methodologies, a number of scholars have argued that post-modernist discourse risks paralysing people from attempting to improve their situation. Kemmis (1995, p.62) has suggested that the “stunned passivity” that some post-modern thought provokes is inadequate to confront the contradictions and unjust conditions that people face in their social lives. Reason and Bradbury (2001c, p.6) cited a similar concern in their suggestion that the deconstructive sentiment of post-modernism does not assist people to better understand the world but rather, alienates people by exacerbating feelings of “rootlessness” and “meaninglessness”. Consistent with this perspective other scholars have argued that ‘pluralism’ engendered in post-modernism largely fails to address “questions of political strategy…[and] structural dominance” (Fals Borda 1994, p.30) as well as how to take action (Lather 1991, p.12). Such concerns acknowledge a real risk associated with post-modernism, that the status quo remains untouched. Kemmis (1995) has emphasised that post-modernist perspectives allow us to be conscious of the partiality and provisionally of our understandings and actions, while also alerting us to the risks of working with others in a critical, communicative space. Critical action research is a method that can facilitate a critical agenda such that aged care staff may come to view their world differently and plan action with a view to changing/improving their situation. As will become evident in the subsequent discussion, the reflexive processes that feature in this method can promote caution associated with post-modern concerns.
3.7 Action research

The previous discussion has detailed the theoretical and conceptual foundations of critical research endeavours of which critical action research is but one of many methodologies underpinned by an emancipatory intent. Action research describes a range of research activities such as participatory research, collaborative inquiry, emancipatory research, action learning, cooperative inquiry and action science – to name a few (Reason & Bradbury 2001c; O'Brien 1998). The diversity of research activities that all reside under the action research banner has made it “notoriously difficult to define” (Hart & Bond 1996, p.153). The illusiveness of a definition has led many scholars (Stringer 1999; Reason & Bradbury 2001b; Kemmis & McTaggart 2003; Waterman et al., 2001) to describe common characteristics of action research such as: collaboration, an interest in local problems, shared ownership of the research and an orientation towards action.

The complexity of the above definition and the multitude of other descriptions that have been offered about action research are suggestive of its diverse origins. The development of action research can be traced from the early work of Kurt Lewin (1890-1947), a social psychologist. He emphasised the need for research in which social scientists and practitioners worked together towards democratic social change through a problem-solving approach (Kemmis 1988; Meyer 1993; Greenwood & Levin 1998; Stringer 1999). According to McTaggart (1991 p.6), Lewin viewed the purposes of social research as having immediate relevance to social issues, such as civil rights and directly challenged the established role of the social scientists as “the disinterested objective observer of human affairs”. Lewin’s action research proceeded through recurring cycles of identifying a problem, planning, acting and evaluating. (Stringer 1999). Waterman et al. (2001, p.1) also pointed out in their review of the origins of action research that Jacob Moreno, a social philosopher, around the same time as Lewin promoted collaborative forms of social research with practitioners as researchers rather than subjects.

In the second half of last century action research was rapidly adopted in the field of education (Meyer 1993). However, it soon fell prey to positivistic critiques. For example, Hodgkinson (1957, p.79 in Kemmis 1988) described action research as having an obsession with ‘doing’, where activity was not aimed at any particular goal but for its own sake. However, during the 1970s there was a resurgence of interest in action research, initially within the interpretative paradigm, through the work of
Laurence Stenhouse and John Elliot (Kemmis 1988; McNiff 1988). During the 1980s Australian educationalists, Wilfred Carr and Stephen Kemmis (Carr & Kemmis 1986; Kemmis 1988), Robin McTaggart (Kemmis & McTaggart 1988; McTaggart 1991; McTaggart & Garbutcheon-Singh 1986) and Shirley Grundy (1988) situated action research explicitly within a critical realm. Grundy (1988, p. 333) articulated that there were three conditions “which are individually necessary and jointly sufficient for action research to exist”. Firstly, the subject matter of the project must be a social practice amenable to improvement; secondly the project must proceed through cycles of planning, acting, observing and reflecting (consistent with Lewinian conception); and thirdly those responsible for practice are involved at all moments of the research process. The ways in which the key characteristics of action research are operationalised within a given study depend on the particular interests with which the particular research is aligned.

3.7.1 Types of action research

Habermas’ (1972) theory of knowledge-constitutive interests has been used as a conceptual basis for delineating the different types of action research (Carr & Kemmis 1986; Boutilier et al., 1997; Grundy 1988; Holter & Schwartz-Barcott 1993). For example, Grundy (1988) placed action research within the three realms of technical, practical and emancipatory. Carr and Kemmis (1986) have referred to "technical”, “practical” and “critical” action research. Other authors have devised categories such as “technical-collaborative”, “mutual-collaborative” and the “enhancement approach” (Holter & Schwartz-Barcott 1993) and “experimental”, “organisational”, “professionalising” and “empowering” (Hart & Bond 1991, 1996). The following discussion considers the different types of action research with reference to technical, practical and emancipatory interests.

3.7.1.1 Action research based in technical interests

Technical interests as advanced by Habermas (1972) and discussed in Section 3.2.1, orientate towards predicting and controlling events in the natural environment. Technical action research is carried out by ‘experts’ or authority figures that enter the field with a pre-determined problem (Grundy 1988, p.355). The researcher, as expert, usually aims to test a particular intervention oriented towards measurable, predictable and repeatable outcomes (Grundy 1988). Kemmis (2001) explained that practice was conceptualised as an “end” in technically-orientated action research. Similarly,
Grundy (1988, p.354) returned to the Aristotelian term *techne* to explain that action arising from this type of research always results from participants operationalising the ideas of the researcher towards an assigned (researcher-prescribed) goal. Interaction between the researcher and the participants is ‘technical and facilitory’ (Masters 1995, p.4). Therefore, various scholars (Carr & Kemmis 1986; Grundy 1988) caution that participants may be coopted by authority figures in existing institutional hierarchies to address questions or issues that serve other external (potentially hegemonic) interests. Success of technical action research is measured by how closely the outcomes reflect the aspirations of the expert-researcher (Kemmis 2001, p.95) and for the most part, broader conditions of practice remain unchanged. The knowledge produced is largely predictive, with a focus on validation and refinement (Holter & Schwartz-Barcott 1993), with the broader conditions of practice largely remaining unchanged (Kemmis 2001).

A key criticism of technical action research is that it does not recognise practitioners’ local knowledge, de-legitimising it in favour of the conceptual parameters developed by an outside expert researcher (McTaggart 1991, p.28). Under these circumstances, participants have little or no autonomy and as such they do not internalise the researcher’s goal as their own (Grundy 1988, p.355). Without participants having a sense of ownership in the research process and its outcomes, the duration of change is usually short-lived (Holter & Schwartz-Barcott 1992). Therefore, once the expert/researcher withdraws from the situation, old ways of working, interacting and thinking tend to re-emerge. Participants are no longer “obliged to act” according to what Grundy (1982 p.356) terms “the action research game” and it is reasonable therefore to call into question the sustainability of interventions and improvements. Praxis development is effectively disabled within a paradigm that values the production of technical knowledge.

### 3.7.1.2 Action research based in practical interests

Practical interests emerge from an interpretative tradition. Habermas (1972, p.176) described practical interests as “aimed at maintaining the intersubjectivity of mutual understanding in ordinary-language communication and in action according to common norms”. Practical interests value people’s “lived experiences” and contribute to “wise, prudent decision making in practical situations” (Kemmis 2001, p.95). Practical action research is aimed at improving people’s understandings of their situation, their practices, and how local and historical knowledge shape their
decision-making (Kemmis 2001; Greenwood & Levin 1998). Practitioners are viewed as the experts in their field and co-participants in a collaborative inquiry. Through shared dialogue the researcher and the practitioners work together to arrive at new understandings of practice, identify problems and develop possible interventions for change (Holter & Schwartz-Barcott 1992, p.301). The role of the researcher within this mode of action research is described by Grundy (1982, p.38) as “…assisting [the practitioners] in the process of self reflection and reasoning”. Unlike technical action research, the knowledge produced by practitioners is descriptive and arises from their mutual understanding. Thus, knowledge is owned by the participants and under these circumstances practitioners are more committed to change processes, having been involved in their development (Holter & Schwartz-Barcott 1993).

Habermas (1972, p.181) has warned however, that interpretative approaches to knowledge development are flawed, as people cannot step outside their own subjectivity. Webb (1996) has explained that the subjective understandings of individuals arise out of a reality where social, economic and political conditions may limit and distort people’s understandings of their world. Thus, a lack of critical questioning within the interpretive paradigm undermines any realisation about how the forms of social interaction and communication may be distorted by dominant ideological interests. Therefore, dominant interests that shape practice remain unproblematised. Carr and Kemmis (1986, p.135) have asserted that “the scope of individuals’ intentions” and their capacity to realise a situation other than the contemporary are limited in practical action research as is the development of praxis as critically informed action.

With the conditions of practice remaining the same, changes and other outcomes of practical action research are linked directly to individuals who are involved in collaboration and action (Holter & Schwartz-Barcott 1993). Changes may be short lived; as individuals exit the setting they take with them the collaboratively-developed knowledge about their situation, its problems and actions for change (Holter & Schwartz-Barcott 1993; Carr & Kemmis 1986). Furthermore, when new people enter the setting who have not participated in defining the problems or shared in knowledge production, their ability to contribute to or continue change processes is limited. Concerns about sustainability are highly relevant to the aged care
environment, where the workforce is characterised by significant turnover (Martin & King 2008).

3.7.1.3 Critical action research – based in emancipatory interests

Action research, informed by what Habermas referred to as an emancipatory interests, has been described as “critical” Carr & Kemmis, 1986; Kemmis 1988, 2001), “empowering” (Holter & Schwartz-Barcott 1993), “enhancement” (Hart & Bond 1996), or “emancipatory” (Grundy 1988; Kemmis 2001) action research. Henceforth, “critical action research” will be used to refer to the approach adopted in the study. As discussed earlier in this chapter (section 3.3), emancipatory interests are orientated towards the investigation and critique of ideology and power within society. Habermas (1974, 1972) argued that critique was the method required to produce emancipatory knowledge. It is a collaborative, dialogic approach through which participants assume self-critical and critically-reflective stances to problems under investigation (Kemmis & McTaggart 1988). Hence, critical action research is conceptualised as a method that could be used by practitioners to understand and challenge dominant power relations (Carr & Kemmis 1986). To this end, it has an interest in the capacity of people to be self-reflective and generate knowledge that will enhance autonomy and responsibility, by transforming subtle, deeply-embedded belief structures that constrain human action (Herr & Anderson 2005; Held 1980).

Critical action research provides opportunities for aged care staff to confront taken-for-granted understandings that support dominant power relations, with the view to transform their situation towards more just and equitable ends. The approach has a predominant concern with “actual not abstract practices” and “concrete problems in practice that arise from particular socio-cultural and material circumstances” (Kemmis & Wilkinson 1998, pp.24-25). Collaboration and reciprocity underpin engagement between the researcher and research participants in critical action research. Research is thus conducted “with and for people” (Meyer 1993, p. 1069) as opposed to on people. The development of critical understandings, that participants have a sense of ownership over can be an empowering process, provoking them to take responsibly for their “own emancipation” (Carr & Kemmis 1986, p.204). From this basis, change within a critical framework is conceptualised as having a higher degree of sustainability than that obtained through practical or technical means Gaventa & Cornwell, 2001; Grundy 1988; Holter & Schwartz-Barcott 1993), being individual and collective. For staff members involved in this project, a critical action
research approach provides opportunities to explore the social, political, cultural and material conditions by which their care practices, for people with dementia, are constructed.

### 3.8 Action research in health care, a case for fluidity

The use of action research in nursing has gained increasing popularity over the past two decades (Coghlan & Casey 2001; Holter & Schwartz-Barcott 1993). With growing concerns in Australia and overseas about the limited impact of research in aged care settings (Meyer 2000; Meyer & Sturdy 2004), action research is viewed as a method to support best practice approaches in RAC (Lindeman et al. 2002; Lindeman et al. 2003; Street 2004). Action research studies in nursing have tended to be technically oriented (Armitage & Evans 2005; Waterman et al. 2001). Holter and Schwartz-Bartott (1993) have highlighted the paucity of nursing research that utilises approaches underpinned by emancipatory interests. However, Hart and Bond (1996, p.57) contended that action research projects may shift between different approaches.

Boutilier, Mason and Rootman (1997) asserted that action research in practice was not static or fixed to one approach. They (Boutilier et al. 1997, p.72) contended that intentions to uphold theoretical purity in an action research project were for the most part impossible due to the complexity of social settings and differing interests that motivated stakeholders. The need for fluidity in the deployment of action research in health care contexts such as RACFs, where staffing issues, resourcing, and workloads are unpredictable, has been noted (Hart & Bond 1996, 1991; Waterman et al., 2001). The cyclical process that participants engage in during action research has been identified as facilitating a certain level of flexibility in the approach (Hart & Bond 1991; Street 2004). Moreover, action research cycles have been identified as having an efficacious role in translating “knowledge/research into practice through reflection and the implementation of change” (Waterman et al. 2001, p.12). The next section describes the conduct of action research as a cyclical process.

### 3.9 Conduct of action research

Action research commences with a “reconnaissance” (Kemmis & McTaggart 1988) or preliminary investigation (Street 2003), and proceeds through a recurring spiral of steps: planning, taking action/collecting data, analysis of data, reflection, replanning and so on (Kemmis & McTaggart 1988).
3.9.1 Preliminary investigation

A preliminary investigation enables practitioners who share a desire to bring about “some kind of improvement or change” (McTaggart 1991, p.170) to form an ARG as well as share and collect information about a “thematic concern” from their practice (Kemmis & McTaggart 1988). For the aged care staff members in this project, the thematic concern related to the possibilities for developing their practices to support a palliative approach to care. In addition, Street (2003, p.224) has explained that a preliminary investigation may involve a number of different activities such as a literature review, eliciting the perspectives of key stakeholders and collection of baseline data that could be used to show improvement. In seeking to gain an initial understanding of the situation in question, Kemmis and McTaggart (1988, p.54) asserted that practitioners should consider how their current practices have been constructed in terms of “language and discourse, activities and practices, social relationships and organisation”. (Kemmis & McTaggart 1988, p.56). Herein, a preliminary investigation should provide an “initial diagnosis” of key issues in relation to the thematic concern, and should also contain some early ideas about a potential collaborative plan of action (Kemmis & McTaggart 1988, p.64).

3.9.2 Planning action

Participants develop plans of action subsequent to the reconnaissance. This involves identifying opportunities for change from increased understandings of the key issues of concern. Action is “critically informed” and as such is a “thoughtful and careful variation on practice” (Kemmis & McTaggart 1988, p.12). Planning action is a prospective process; it needs to be done systematically and be situated in a rationale from the group’s understandings of the situation (Street 2003, p.224).

Kemmis and McTaggart (1988, p.12) have explained that critically informed action is “risky” and can encounter a range of real world (material, political) constraints. Therefore, action plans should be flexible and amenable to modification as new circumstances arise (Kemmis & McTaggart 1988; Street 1995, 2003). McNiff (1988, p.44) asserted that action research should have the capacity to deal with more than one problem at the same time and therefore plans should be able to accommodate “spin off” cycles from the main concern. Street (2003, p.225) cautioned that actioning more than one plan at a time may make it difficult to discern the source of the outcome. However, she (Street 2003, p.227) also acknowledged that some
projects may include sub-spirals that pursue specific objectives to develop more comprehensive understandings of the research problem and ways to address it.

The planning phase takes into careful account the subjective and objective conditions of practice (Street 1995; Kemmis & McTaggart 1988; Street 2003). Street (2003, 1995) has highlighted that participants could develop an action plan by focusing on a series of key questions that assist them to (i) articulate what they want to change, including a rationale; (ii) plan systematic action; (iii) interrogate the feasibility of the plan; (iv) determine what data will be collected and how; (iv) decide what the expected outcomes will be; and (v) develop methods of monitoring and assessing the outcomes. According to Kemmis and McTaggart (1988, p.65), deciding where to first take action is a “strategic decision” on behalf of the group of participants. Therefore, planning action may consist of compromise on some levels in order to initially achieve “modest gains” (Kemmis & McTaggart 1988, p.12) that may then be built upon in later action cycles.

3.9.3 Taking action and observing/collecting data

During this stage of the action research cycle participants simultaneously engage in both practice and the action plan. Kemmis and McTaggart (1988, p.78) have asserted that it is not unusual, especially during the first action cycle, for unforeseen circumstances to arise and an early replan to be required. Regardless of whether the action is implemented as originally planned or modified early during the action process, monitoring of the action is essential. Observing the action and collecting data provides a basis “for later reflection and replanning” (Kemmis & McTaggart 1988, p.78). There are no set techniques for data collection, and a mixed method approach is often employed (Street 1995). Monitoring facilitates the collection of data about both the intended and unintended or unforeseen effects of the action (Kemmis & McTaggart 1988; Street 1995). The researcher, keeping a personal/professional journal, has also been flagged as another important source of data about the action.

3.9.4 Analysis of data and reflection

Depending on the types of data collected the researcher may undertake some of the initial analysis, where specific data analysis skills are required (e.g. statistical analysis of surveys) (Street 1995). Pragmatic decisions may also be made in relation to time and resourcing constraints (Street 1995) meaning that the researcher
resources the ARG by way of conducting a first level analysis of data. However, while the researcher may present an initial account of the findings may be presented to the participants by the researcher, Kemmis and McTaggart (1988, p.85) caution that the researcher provides a “dispassionate account” of what actually happened. However, further meaning-making must be a shared endeavour, so that the participants have an opportunity to reflect on the data. In the case of this project, RACF staff were able to reflect on their actions with respect to best-practice standards and wider socio-political conditions shaping their practice. Critical reflection on the data can reveal gaps between staff members’ “espoused theories” that represent what people say they do and their “theories in use” that become evident from their actions in practice (Argyris & Schon 1974; Friedman 2001). Reflection can foster the development of new insights among participants about their taken-for-granted assumptions, and habitual practices may be challenged. Critical, collaborative understandings can empower co-researchers to replan and implement action that pursues improvement through a successive spiral (Kemmis & McTaggart 1988).

Reflection also occurs on the research process itself and the roles of those participants involved. From this perspective “the interest is not only what is discovered but also how it was discovered” (Street 1995, p.226). At the completion of the reflective phase participants decided if a revised action plan from the previous cycle should proceed following amendment or whether a new action plan related to the areas of concern should be developed. Importantly, Waterman (2005) has emphasised that an iterative approach between action, analysis and critical reflection can facilitate the development and refinement of action-sensitive theory.

The steps of planning, taking action/collecting data, analysis of data and reflection and planning are often presented as being discrete. However, in reality there may be overlap between some of the stages and the process is likely to be “more fluid, open and responsive” (Kemmis & Wilkinson, 1998 p.21).

3.10 Monitoring change

Monitoring change within an action research project is complex and requires a multi-dimensional perspective to be adopted by the participants (Kemmis & McTaggart 1988; McTaggart 1991; Kemmis & McTaggart 2003; Mattsson & Kemmis 2007). Kemmis (2007, p.1) has explained that action research aims at changing “people’s
practices, their understandings of their practices and the conditions under which they practice”. To measure change in action research projects, changes in understandings are expressed through language, changes in practices are evident in the activities undertaken by people, and changes in conditions of practice are expressed in changing relationships of power (Kemmis & McTaggart 1988, p.40).

In recognition that people are essentially social beings (McTaggart 1991; Kemmis & McTaggart 1988), cultural change requires individuals to contest and change how they use language, how they interact with each other and the patterns of social relationships they form. Thus change is understood as individual, collective and collaborative (Kemmis & McTaggart 1988). Monitoring change and improvement requires co-investigators to analyse how language activities/practices, and social relationships/forms of organisations are contested and institutionalised during the research process. Within this study, change may occur across some of the categories outlined in Table 1.

Table 1  Framework for monitoring change

<table>
<thead>
<tr>
<th>Registers of Change</th>
<th>Change Categories</th>
</tr>
</thead>
</table>
| Language/understandings              | • Development of new understandings, as reflected in co-researcher’s use of language about how care is delivered to residents.  
• Changes in co-researcher’s understandings of how taken-for-granted ways of practicing, undermine/constrain their capacity to provide care consistent with a palliative approach.  
• Changes in the ways that co-researchers talk about action research.                                                                                                                                                                                                                       |
| Activities/practices                 | • Changes in the practices of co-researchers, to reflect best practice standards for a palliative approach to care.  
• Formation of different patterns of activity between co-researchers in care provision.  
• Changes in co-researchers participation in the action research process.                                                                                                                                                                                                                   |
| Social relationships/Forms of organisation | • Changes in relationships between co-researchers and with others (colleagues, family caregivers, Residents, management) in the provision of care.  
• Changes in the power relations between co-researchers.  
• Development of networks that assist co-researchers to change and improve their practices consistent with a palliative approach to care.                                                                                                                     |

While not exhaustive, the above categories provide a framework for monitoring change and improvements resulting from SCU staff members’ participation in the
research. Improvements occurring through processes of contestation and institutionalisation often happen slowly through “struggle” and incremental change (Kemmis & McTaggart 1988, p.26). Careful critically reflective analysis, guided by categories of change, can facilitate the development of “records of improvement” (Kemmis & McTaggart 1988, p.25) that chronicle the empowerment of aged care staff.

3.11 Tensions in the conduct of critical action research

3.11.1 Constructions of facilitation

A number of authors have recognised that working with practitioners as co-investigators requires careful consideration on behalf of the researcher as to how best assist and support them through action research processes (Lindeman et al. 2003; Robinson & Street 2004; Meyer 1993; Titchen & Binnie 1993; Koch & Kralik, 2006). Given the “traditional hierarchy” (Lindeman et al. 2002, p.29) often pervading RACFs, the role of a facilitator in action research is crucial to ensuring the opening of a dialogic space where all practitioners have an opportunity to be heard.

Wadsworth (2001, p.232) has referred to facilitation in action research as a process where the researcher may “‘keep watch’ and take actions to ensure…things happen for others, individually and collectively”. Consistent with democratic, collaborative imperatives underpinning action research, facilitation can engender a shared inquiry where the researcher journeys with practitioners as co-investigators. For people such as aged care staff, who have not previously engaged in action research, it is recognised within the literature (Gibbon 2002; O’Conner 1987; Waterman et al. 2005; Kelly & Simpson 2001; Morton-Cooper 2000) that the key role of a facilitator is to assist staff to develop research capacity and proficiency. Waterman and colleagues (2005) reported that in the first phase of their action research project, the facilitator regularly explained action research and the respective roles of participants. Likewise, a key aspect of my role as a facilitator was to introduce group members to the action research process, enabling them to become familiar with the approach, its theoretical foundations and their participation as co-investigators.

Waterman (2005) and Kelly and Simpson (2001, p.653) acknowledged the importance of some degree of leadership offered by a facilitator, especially in the early stages of the research. Action research is conducted in the “real-world”, where inconsistencies and unpredictability emerge from complex organisational processes.
and struggles between groups with differing interests (Morton-Cooper 2000, pp.14-15). Street (2003, p.330) highlighted that the type of facilitation in action research projects conducted within RAC settings, could be dramatically influenced by the “socio-political climate of regulation and accreditation”. For example, changes in documentation and accreditation processes may place additional demands on staff members, reducing their capacity to participate in the research, in turn requiring the researcher to collect and analyse the majority of data. Additionally, Lindeman (2003, 2002) has reported that aged care staff as novice co-researchers benefit from facilitation that gives them direction to identify common goals. Consistent with Wadsworth (2001), as the facilitator in this project I constructed my role to assist participants to map their shared experiences and concerns that connected them to a common purpose toward improvement. Equally, my role included assisting the co-researchers to recognise sources of ambiguity or conflict in their practices. Thus, I identified my role with the following description offered by Holter and Schwartz-Barcott’s (1993, p.302), who stated that within an empowering type of action research, the researcher:

Facilitates practitioners’ discussion of underlying problems and assumptions on a personal level as well as the level of the organisation’s culture and possible conflicts they can generate. The emphasis…is on bringing to the surface the underlying value system, including norms and conflicts which may be at the core of problems identified.

Similarly, Wadsworth (2001) acknowledged that a facilitator could assist practitioners to focus their attention on previously unconsidered or unchallenged assumptions. McCormack and colleagues (1999, p.260) use the term “critical companion” to highlight this essential component of a facilitator role. Thus, I constructed my role to support participants to develop shared understandings about factors that enabled and constrained their practice development. By developing a safe dialogic space, where a “talking culture” (Meyer 1993, p.1070) could be fostered, I supported the participants to develop their skills in critical reflection by posing questions and provoking them to interrogate their own and other’s practices during the research process. Accordingly, facilitators have a central role in resourcing co-investigators to support their development of critically reflective skills and the progression of the research (Wadsworth 2001; Morton-Cooper 2000). For example, my role in resourcing participants in this project involved activities such as
compiling meeting minutes and case notes that group members could use as a source for critical reflection; providing guidance and assistance with respect to methods of data collection, aspects of reporting and access to information networks.

Finally, within the context of an empowering agenda Wadsworth (2001, p.330) has highlighted the importance of a facilitator being someone who can “hold the needed liminal spaces” between reflection and action so that staff members can arrive at “transformative moments”. When working with aged care staff in this project my role also included encouraging and assisting them to engage in reflection and critically-informed action. Street (1995) has pointed out that nurses are familiar with thinking on their feet and having to deal with rapidly changing situations. Thus, participants who have not been involved in action research before have a tendency to take immediate action when a problem is identified (Street 1995, 2003). As a facilitator, especially within the earlier phases of the research it was important for me to support staff to construct comprehensive, critically informed understandings of their situation and to recognise incremental change as a foundation for future praxis.

### 3.11.2 Challenges to facilitation

Critical action research is a political process (Coghlan & Casey 2001; Williamson & Prosser 2002; Mason & Boutilier 1996; Meyer 1993) and challenges associated with power relations that exist within the research group and the research process have been well documented in the literature (Beattie et al. 1996; Reason 1998; Lax & Galvin 2002; Mason & Boutilier 1996). For this reason, the facilitation of action research projects has been associated with tensions arising from the “politics of collaboration” (Beattie et al. 1996, p.682). Meyer (1993) raised concerns about the extent to which facilitators could actually work with participants and whether power imbalances between the researcher and participants could be redressed. Mason and Boutilier (1996) presented similar concerns, when they explained that despite their efforts to establish egalitarian relationships and processes between the researcher and participants, power imbalances could not be overcome. Hence, the political nature of participatory research processes needs to be acknowledged at the outset of this research, otherwise there is a risk, as Mason and Boutilier (1996, p.150) have pointed out, that issues of power “may be driven underground” and re-emerge in other guises. Asymmetrical relations between the research group and the facilitator (Meyer 1993; Mason & Boutilier 1996), especially at the beginning of a project have been recognised as a threat to the aspirations of participant ownership over the research.
process. Mason and Boutilier (1996, p.149) highlighted that researchers occupy an “elevated status” as outside experts in command of research skills, knowledge and understandings of research expectations. In this sense my position in the study was in part one of an “outsider” or as Meyer (1993, p.1070) explained an “academic expert belonging to another world”. Embedded within this role is the potential to paradoxically disempower research participants. Drawing on the work of Brookfield (1993), Beattie and colleagues (1996, pp.684-685) explained that by the researcher being viewed as the “expert”, participants may feel a sense of “impostorship” whereby they consider themselves unqualified to participate in the project and thus struggle to find a voice. Koch and Kralik (2001) have explained that despite best intentions a facilitator may impose their own interests onto an already vulnerable group. This is important as inexperienced researchers are identified as being at greater risk of this (Koch & Kralik 2001, p.28). These are vital considerations with respect to my facilitation role as I was in part an insider to the research setting. Having previously worked as a nurse on the SCU and on other units at the RACF, I brought a range of assumptions to the project and as such I needed to be vigilant in examining how these came to bear on the research (section 4.4.1.4 further addresses this issue).

Another challenge in facilitating action research is the potential to disempower research participants through the creation of dependence (McTaggart & Garbutcheon-Singh, 1986). In support of this concern, Mason and Boutilier (1996) explained that an outside researcher or facilitator may be viewed by participants as more influential in negotiations with the organisational hierarchy and having “greater latitude” to suggest changes. Such circumstances jeopardise the empowerment of participants, the development of egalitarian relationships between participants and the researcher, and the aspirations of a critical project overall. The potential for dependence alerts the facilitators of participatory projects to be attentive to moments (later in the research) when their obsolescence can be explored (Henry & Henry 1988). From this perspective, my role as a PhD candidate meant that I would inevitably withdraw from the research setting to write-up my thesis. Therefore, it was important in my facilitation role to assist group members to engage in critical dialogue that encouraged the development of a “group commitment” (McTaggart & Garbutcheon-Singh 1986) that had the potential to sustain them as a self-organising “community of inquiry” (Friedman 2001). However, as part of the process the ability of participants to meet regularly over a sustained period of time was imperative. The
absence of sustained engagement would jeopardise the progress of these endeavours because collaborative, reciprocal relationships between people have been recognised as essential for the successful conduct of critical action research (Meyer 1993). This was of particular concern to me as a facilitator, given the issues identified in Chapter Two about the impact of workloads, short staffing and increasing casualisation of the workforce.

Despite the tensions inherent in adopting a critical action research method to guide this study, it was a method of best fit to investigate the possibilities for developing the practices of staff working on a dementia SCU around a palliative approach to care (ADoHA 2006). Characterised by democratic, participatory, collaborative and critically reflective processes, critical action research seeks to bring together action and reflection, theory and practice (Reason & Bradbury 2001c, p.1). This dialectical relationship can offer a range of possibilities to the staff members involved in this project, for change and improvement.
Chapter 4: Research Design

This chapter provides a demographic overview of the research field and specific details about the research site. Considerations relevant to the pragmatics of conducting an action research project in conjunction with a PhD are discussed to highlight how these circumstances also shaped some of the initial project activities. Information about recruitment and the characteristics of the ARG members are provided, as well as details about the establishment and characteristics of the steering committee that oversaw the project. An overview of the structure of the study, data collection and analysis techniques are outlined. A discussion on issues of validity and the ethical considerations relevant to the conduct of action research concludes the chapter.

4.1 The research field

4.1.1 Demographic profile of Tasmania

This project was conducted in Tasmania, where, similar to other states in Australia, there is an ageing population (Access Economics 2005). Tasmania is the state with the oldest population profile in Australia (Access Economics, 2005). Projections indicate that by 2050 the number of people with dementia in Tasmania will have increased approximately three-fold from 4,600 in 2000 to 14,600 (Access Economics 2005). There will undoubtedly be a concurrent increased pressure on community and RAC services. Conducting research with RACF staff in Tasmania, is crucial to developing a capacity in the sector to meet the needs of older Tasmanians with dementia and their family caregivers.

4.1.2 Characteristics of the RACF and the dementia Special Care Unit

This project was conducted in one dementia SCU that was part of a larger metropolitan RACF in Tasmania. The RACF provided more than 100 beds, being in the top 10% of RACFs in Australia for this size (Productivity Commission 2010, p.11). At the commencement of fieldwork for the study, all residents in the facility were classified (i.e. according to their RCS rating) as having “high care” needs (reflected by RCS categories1 to 4). Data that was available from the RACF about the profile of staff providing care is presented in Table 2.
Table 2  Profile of staff at RACF (N=160)

<table>
<thead>
<tr>
<th></th>
<th>Permanent full-time</th>
<th>Permanent part-time</th>
<th>Casual</th>
<th>Total % of RACF workforce*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered Nurse (n=18)</td>
<td>2 (senior management)</td>
<td>11</td>
<td>5</td>
<td>11.2%</td>
</tr>
<tr>
<td>Enrolled Nurses (n=17)</td>
<td>0</td>
<td>13</td>
<td>4</td>
<td>10.6%</td>
</tr>
<tr>
<td>PCAs (n=94)</td>
<td>0</td>
<td>64</td>
<td>30</td>
<td>58.8%</td>
</tr>
<tr>
<td>leisure and Lifestyle Officers</td>
<td>0</td>
<td>6</td>
<td>0</td>
<td>3.8%</td>
</tr>
</tbody>
</table>

*Service employees (catering, Laundry, maintenance, administration) account for the remaining 15.6 % of total facility staff.

The SCU where the study was undertaken contained 35-40 beds. For the purposes of anonymity the actual bed number has been omitted. At the time of the fieldwork all beds in the SCU were occupied and the dependency profile (RCS - see p. 15 for discussion about RCS ratings) of residents was as follows:

- 24% of residents classified as RCS 1 (highest level of care)
- 56% of residents classified as RCS 2
- 18% of residents classified as RCS 3 (note: data for RCS category for one resident on the SCU was unable to be obtained)

With 80% of residents having care needs that placed them within the two highest care categories, this data indicates a highly dependent unit-based population. The staffing profile (of RNs/ENs and PCAs) per shift for the SCU is represented in Table 3.

Table 3  Staffing profile for SCU per shift, equivalent full-time

<table>
<thead>
<tr>
<th></th>
<th>Morning</th>
<th>Afternoon</th>
<th>Night</th>
</tr>
</thead>
<tbody>
<tr>
<td>EFT RN/EN PCA</td>
<td>1 4.5</td>
<td>1 3.5</td>
<td>0 2</td>
</tr>
</tbody>
</table>

As further explanation to the above table, on a morning shift their would either be one RN or one EN in charge of the SCU; four PCAs were rostered to work the entire
shift (eight hours) and one PCA would be rostered for four hours of the shift (usually during the busiest time when resident activities of daily living were attended too). The SCU is situated within a larger facility that has a number of other high-care units. Each shift is overseen by an RN Supervisor. Therefore, ENs working a morning or evening shift are under the indirect supervision of the RN supervisor. On night duty the RN supervisor is responsible for the SCU, and usually three other units in the facility as well. It is evident from SCU staffing and resident profiles that the majority of residents were highly dependent and the majority of care provision was provided by PCAs. These factors were important sources of consideration when setting up the project.

4.2 Setting up the study

As a PhD candidate, the practicalities of my role within the project meant that I was required to fulfil a number of institutional/academic expectations. At the beginning of the project I broadly defined a research question, gained access to the research setting and was responsible for recruiting participants to form an ARG. The pragmatics of undertaking a PhD dictated that a certain amount of technical management and organisation at the beginning of the project was necessary.

4.2.1 Defining the research question

As discussed in Chapter 1, I started my PhD candidature with a desire to explore how palliative care could be improved for people with dementia. Importantly, it was also a concern that was shared by my co-workers in the sector. Hence, consistent with a guiding principle of action research Waterman et al., 2001) this study aimed to address a local problem. Coghlan and Casey (2001) have highlighted that the way in which an issue is framed in an action research project is important as it can have implications for how participants understand it and approach the investigation. While no issue is context- or value-free, in keeping with the concerns raised by Coghlan and Casey (2001) I crafted a broad research question: What are the possibilities for the practices of aged care staff to be developed to better support a palliative approach to care for people with dementia?. Conducting a literature review assisted me to frame the area of inquiry with respect to the current knowledge in the field and limitations in this knowledge base. After reviewing the literature I posed three sub-questions that reflected gaps in the literature. The questions provided a general guide for the direction for the project and a loose framework from which discussions could
emerge about issues that staff considered important and warranting attention. The questions were:

- Is a palliative approach to care understood and reflected in the practices of aged care staff on the SCU?
- Are there factors/conditions that constrain aged care staff from delivering an evidence-based palliative approach to care in the SCU?
- What strategies will enable/support aged care staff to develop their practices around an evidence-based palliative approach to care?

4.2.2 Entering the research setting and formation of the Action Research Group (ARG)

As previously discussed in Chapter 3, the involvement of practitioners is central to the collaborative and participatory imperatives of critical action research. In keeping with the collaborative imperative of critical action research (Carr & Kemmis 1986; Street 2003), the formation of an ARG was a critical step in setting up the project. I negotiated access to the SCU in consultation with the facility manager and undertook activities to recruit staff members. Information flyers were placed on the noticeboard of the SCU to inform staff about the upcoming project and invite them to attend the next staff unit meeting if they were interested in participating (Appendix 2). I conducted two information sessions at staff unit meetings, where I discussed the research aims, important aspects of participant involvement, issues related to confidentiality and anonymity and gave a brief description of the research methodology. Staff members were eligible to participate as members of the ARG if they:

- were a RN, EN or PCA;
- had at least 12 months in their current position; and
- were a permanent staff member (either full-time or part-time).

The above eligibility criteria were established to take account of a number of key features of the RAC workforce. Firstly, PCAs comprised the majority of staff on the SCU and provided the bulk of direct care provision (Richardson & Martin 2004). Therefore, the inclusion of these staff members was considered crucial to supporting the collaborative and democratic imperatives of critical action research and developing a comprehensive analysis of the situation under question. It was likely that any changes on the SCU would have some impact on PCAs. Moreover, RACFs
are recognised as being traditionally hierarchical environments, where PCAs historically have limited opportunities to voice their concerns with respect to practice (Lindeman et al. 2002; Jervis 2002). It was anticipated that PCAs could bring important perspectives about the social-political environment of the SCU that did not solely reflect the hierarchical interests in the setting. Finally, in recognition of the transience and increasing casualisation of the aged care workforce (Richardson & Martin 2004), the inclusion criteria, that staff members occupy a permanent position and be employed in their position for at least 12 months, were used in an attempt to establish an ARG that comprised a stable group of staff, albeit not representative of other staff groups working with the RACF.

At the SCU staff meetings I distributed research information sheets (see Appendix 3). Staff members interested in participating as ARG members were encouraged to contact me to make an appointment. At these subsequent appointments I discussed with the potential participants the importance of sustained and committed engagement within the research. Kelly and Simpson (2001) have pointed out that in reality, participation in action research projects often means that extra demands are placed on staff time and energies. From this perspective, I had an ethical responsibility to ensure that potential participants were well informed about my expectations, the degree of time commitment (e.g. 1 hour focus group meeting per fortnight) and the possibility that their level of participation might fluctuate during the project.

From a total of 35-40 staff members who worked regularly on the SCU, seven staff approached me to participate in the project, these being four PCAs, one RN and two ENs. Two of the PCAs declined to participate after having met with me, one through illness and another because of her stated lack of confidence in voicing her views in the presence of nursing staff from the SCU. Recruitment activities were completed by the end of March 2006 and the ARG comprised two PCAs, one RN and one EN. The ARG continued to go through changes in membership following an initial preparatory meeting held in early April. Some within the ARG voiced concerns about the absence of a senior clinical staff member in the group, suggesting that research activities might be afforded only low significance amongst the many demands of daily practice. The involvement of staff members who hold influential positions in the research setting has been highlighted as strategically important to facilitate progress of an action research project (Waterman et al. 2001). ARG
members identified a RN supervisor who they considered would be supportive of the study. Coincidentally, this staff member had agreed to sit on the project steering committee (further information about the steering committee is provided below). I reapproached the RN supervisor, who subsequently agreed to participate. Demographic information about the ARG members is outlined in Table 4.

<table>
<thead>
<tr>
<th>Position</th>
<th>Age Range (yrs)</th>
<th>Time in current position (yrs)</th>
<th>Time in aged care overall (yrs)</th>
<th>Qualifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Judy</td>
<td>RN</td>
<td>≥ 46</td>
<td>6-10</td>
<td>≥ 15</td>
</tr>
<tr>
<td>Heather</td>
<td>RN</td>
<td>≥ 46</td>
<td>11-15</td>
<td>11-15</td>
</tr>
<tr>
<td>Anne</td>
<td>EN</td>
<td>35-45</td>
<td>11-15</td>
<td>≥ 15</td>
</tr>
<tr>
<td>Catherine</td>
<td>PCA</td>
<td>≥ 46</td>
<td>11-15</td>
<td>11-15</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>PCA</td>
<td>35-45</td>
<td>6-10</td>
<td>6-10</td>
</tr>
</tbody>
</table>

I have used pseudonyms and some data about hours and shifts worked per week (e.g. morning, afternoon, night) has been omitted from Table 4 to maintain staff members’ anonymity.

4.2.3 Developing research capabilities of ARG members

Following the recruitment of the ARG members I conducted three one-hour education sessions with them. These sessions were developed in consultation with my primary supervisor and introduced ARG members to the action research process, assisted them to become familiar with the basic conceptual foundations of the method and provided a more detailed introduction to the research question and rationale. These preparatory activities were important as they provided the ARG with opportunities to explore the action research process, making it more “accessible” (Brown et al. 1988, p.341) to them as novice researchers. Given that the group members had never before been involved in action research or other such forms of participatory inquiry, assisting them to build their capability to engage in the research process, prior to beginning the fieldwork, was essential. At the completion of the first
session I journalled that: as group members learnt about action research they started to discuss problems from practice that they believed should be addressed, sharing suggestions...however they were also quite interested to know what my motivation for undertaking the research was (Researcher Journal April 1, 2006).

As evident in the above account the education sessions also provided important opportunities for me to share with the ARG my interest in conducting research both as a clinician, who shared similar concerns to them, and as an aspiring a PhD candidate. Providing members with insights into my circumstances contributed to establishing a sense of reciprocity early within the project. I journalled that, discussing my motivations with the ARG was met by them with a very positive response and also an understanding that my role was to work with them to open a space where issues could be discussed (Researcher Journal April 1, 2006).

During the initial ARG meetings I also raised with members some ground rules for group meetings and data management. These discussions addressed concerns about confidentiality of issues discussed in the context of research meetings, so that all members had a sense that the meetings were a safe space to raise issues. We agreed that all case notes would be distributed electronically so that hard copy data pertaining to discussions was not circulated. I also discussed with members the ways that they thought they could establish a collaborative agenda in which all members had equal opportunities to speak freely. These discussions with members were important to establishing a “safe environment” (Cornwall & Jewkes 1995, p.1669) where they felt comfortable engaging in dialogue. Through their discussions, the members also negotiated a meeting location within the RACF that was removed from the SCU, so as to minimise disruption and to avoid what members described as ‘suspicions’ of other staff members about them meeting together.

4.2.4 Establishment of the project steering committee

In tandem with setting up the ARG, I facilitated the establishment of a project steering committee. In research that promotes collaboration between different stakeholders, the establishment of a steering committee is important to initiate involvement and encourage commitment from people in positions of authority (LeGris et al. 2000). The involvement of steering committee members ensured that experts in the field had input into the study, by means of providing support, guidance and feedback to the ARG. Letters of invitation were sent to key stakeholders
identified by me in consultation with experts from my PhD supervisory team. The terms of reference for the steering committee that were set out in the letters of invitation were as follows:

- To monitor research activities and provide feedback where appropriate.
- To be a resource to the research group by promoting access to information networks and key respondents.
- To promote access to key decision-making committees to facilitate the planning and implementation of action.
- To make recommendations on issues of concern related to the research.

The steering committee comprised the following stakeholders:

- Nurse manager of the facility;
- RN supervisor from the facility;
- General Practitioner who regularly visits SCU;
- Medical specialist from palliative care services;
- Nurse specialist in dementia care;
- Allied health staff member from the facility;
- Consumer representative;
- Representative from the Department of Health and Ageing; and
- Professor of Nursing.

Three steering committee meetings were held across the course of the project approximately 6 months apart. Communication with the steering committee members was initiated and facilitated by me during the course of the project, as it was not possible for group members to assume these responsibilities in addition to their participation in other project activities.

4.3 Structure of this study

The project was structured in three stages between March 2006 and November 2008. The three stages reflect the developing engagement of the ARG members, from a process that was initially “researcher facilitated” (Robinson 2001) to one that embraced a critical, empowering agenda.
4.3.1 Stage One: Preliminary investigation: a facilitated engagement (April 06 – Jan 07)

In Stage One of the study the ARG members participated as novice action researchers, being largely unfamiliar with the research process. This meant that in my role as a facilitator I supported the group to engage in collaborative dialogues and assisted them to develop their proficiency in action research. Given that I had prior experience and knowledge of research, the majority of the responsibility for facilitating a preliminary investigation fell to me. Hence, this Stage consisted of reconnaissance discussions whereby ARG members engaged in collaborative dialogue (through regular meetings) to explore issues relevant to the provision of palliative care for people with dementia and their family caregivers in the SCU. These initial findings were presented to the project steering committee for their review and feedback. Following this, more detailed data was collected from a number of different sources (Action Cycle 1), to scope key issues that had emerged from the reconnaissance about staff and family knowledge of dementia and a palliative approach as well as the documentation of care practices. The ARG members reflected on the findings of Action Cycle 1 to identify four problem areas in need of improvement.

4.3.2 Stage Two: Emerging empowerment (Feb 07 – April 07)

Stage Two chronicles the ARG members’ growing sense of confidence and empowerment in the research process as they took the lead in developing a series of intervention strategies. During this time the ARG divided into two research subgroups and conducted independent planning meetings, engaged in data collection and analysis activities to develop four evidence-based intervention proposals (Action Cycle 2). Subsequently, the intervention proposals were presented to the project steering committee (Action Cycle 3). As the proactive stance of the ARG evolved during this stage, I occupied a position more akin to a critical collaborator with ARG members.

4.3.3 Stage Three: Reconfiguring practices (May 07 – Dec 07)

In Stage Three of the project ARG members acted on the feedback from the steering committee and assumed responsibility for the implementation of the four intervention strategies. These included: staff education sessions (Action Cycle 4); information given to family caregivers (Action Cycle 5); piloting of a new pain
assessment and management strategy (Action Cycle 6) and piloting a palliative care planning intervention (Action Cycles 7 and 8). The ARG members embraced their roles as co-researchers and met at various points to report and critically reflect on their progress. I met with members during this time to reflect the study findings.

4.4 Data collection

4.4.1 Core data collection

In this study a number of core data collection strategies were employed during the entire period of field work. These strategies were embedded within all action cycles and included ARG meetings (including reflections on case notes), steering committee meetings, my research journal and co-researcher field notes. These data were used by the ARG members to iteratively inform the direction of the project, while also serving as records of progress.

4.4.1.1 ARG meetings:

Meetings with the ARG members provided a primary source of research data during the course of the project. A total of 28 ARG meetings were held, constituting over 30 hours of recorded discussions. These meetings provided opportunities for ARG members to engage in critical dialogic encounters. Meetings were interactive so that the traditional hierarchical relationship between myself (as researcher) and the ARG members could be minimised (Fontana & Frey 2003, p.83). Consistent with the theoretical underpinnings of critical action research, Oakley (1981 p.49) pointed out that in dialogic engagements there was “no intimacy without reciprocity”. Hence, during the ARG meetings I asked many questions of the members and interrogated their understandings; I also shared my concerns and feelings about the issues under study. Fontana and Frey (2003, p.83) emphasised that such an approach could provide “a greater spectrum of responses and greater insight into the lives of respondents”. Moreover, Lather (1991, p.64) contended that such interactive discussions opened a space for “reciprocal reflexivity and critique” so that the ideas of one member in the discussion were not imposed on the other.

Meetings were initially in a meeting room at the RACF so that ARG members could attend either prior to or at the completion of their shift. During the early meetings I encouraged members to reflect on their practice by asking broad non-threatening questions such as “can tell me about your experiences of working on the SCU?”.
“can you tell me what it’s like caring for people with dementia?” These types of open-ended questions provided opportunities for members to share stories which were familiar, comfortable, and affirming of their ‘lived experiences’ (Van Manen 1990). At points during the initial ARG meetings I strategically intervened to make space in the discussion for Elizabeth and Catherine (both PCAs) to be heard. For example, when some of the discussions were dominated by the nursing staff in the ARG (Heather, Anne and Judy), I would respond to their concerns by asking Catherine and Elizabeth for their contribution. Facilitating the meetings so that members had opportunities to share their concerns and ideas was at times challenging, as the force of discussion was lively. Nonetheless, it was an important part of my facilitation in the early meetings, given that neither of the PCAs had ever met before with nursing staff to share their concerns about practice. Table 5 outlines the number of meetings held in each stage of the project and members’ attendance rates by percentage.

Table 5  Number of ARG meetings, each stage of the project

<table>
<thead>
<tr>
<th>Stage</th>
<th>ARG meetings (n=27)</th>
<th>Attendance rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1 (April 2006-Jan 2007)</td>
<td>11</td>
<td>84</td>
</tr>
<tr>
<td>Stage 2 (Feb 2007- April 2007)</td>
<td>7 (including a 3hr workshop)</td>
<td>71</td>
</tr>
<tr>
<td>Stage 3 (May 2007 – Dec 2007)</td>
<td>9</td>
<td>71</td>
</tr>
</tbody>
</table>

Reflective of the ARG’s increasing independence over the course of the study, their meetings were markedly less frequent during stage three, occurring approximately once per month, At these meetings members discussed implementation activities, provided feedback on their progress and critically reflected on the impact of the interventions. All of the research meetings were digitally recorded and transcribed by me. The data underwent thematic analysis.

4.4.1.2 Case notes

The preliminary thematic analysis of the ARG meetings was reported in case notes that were returned via email to group members prior to the next ARG meeting. The
Electronic distribution aimed to maintain confidentiality of the research discussions and reduce the circulation of hard copies of the data.

Returning case notes to the ARG prior to the subsequent meeting was a strategy designed to provide members with an opportunity to:

1. review the content of the case notes for accuracy (member check); and
2. critically reflect on their accounts of practice contained within the case notes.

On average case notes were 4,000-5,000 words in length. Therefore, each ARG meeting had to be transcribed and case notes developed within a week following its conduct (during times when the meeting were held fortnightly) so that ARG members were given enough time (approximately a week) to review the case notes prior to the next meeting. At these meetings members were given the opportunity to make amendments to the case notes, offer additions or further clarify issues that had been discussed. They were also asked to endorse whether the case notes were an accurate reflection of discussions that took place during the meeting.

4.4.1.3 ARG meetings to facilitate planning (Action Cycle 2)

A three-hour meeting of ARG members was conducted in Action Cycle 2 during which they designed a number of intervention strategies to address identified concerns. This meeting took the form of a planning workshop. In addition to members’ reflections in this meeting, they explored areas of intervention by addressing a number of key planning questions (Street, 1995), these being:

1. Why is this action important/how is it going to make a difference?
2. What do you think will be the outcome of the action?
3. What could go wrong/What are the constraints/What are the risks? (How will you negotiate these?)
4. How will you report what happens as a result of the action?
5. Who will be responsible?

I facilitated these discussions and used butcher’s paper to document the ARG’s key responses to each of the planning questions. The workshop was also audio-recorded. Members’ deliberations during the workshop yielded a working document that
contained four areas of strategic action, crafted through their responses to the planning questions (see Appendix 4).

4.4.1.4 Steering committee meeting minutes

Minutes from the steering committee meetings were kept by me and a member of the ARG who attended. This data provided the other members with access to the discussions and decision-making processes that helped shape the activities and directions of the ARG.

4.4.1.5 Researcher journal

The use of reflective field notes or journals has been advocated as a method of establishing critical self-awareness in the research process (Street 1990, 1995). I started the process of keeping a research journal within the first couple of months of commencing my PhD candidature. Subsequently, as I accessed literature about reflexivity in the research process (Rowan 2001; Lather 1991; Hall 1996), and in recognition of my partly ‘insider status’ to the project, the necessity of exploring the ideological assumptions that I brought to the research became increasingly apparent. Regular journalling throughout the early stages of the PhD helped me to examine my biases and assumptions.

Moreover, in research that has an interest in charting the politics between the researcher and participants, such as critical action research, a journal provides an important means of data collection and analysis. Kemmis and McTaggart (1988, pp.50-51) have articulated that journals should contain reflections about:

- changing uses of language…changing activities…changing social relationships,
- changes to the formal organisational structure… and changes in the way the group is participating in the action research process itself…

My journal contained descriptions of activities during the research, some of which I shared with the ARG members, as well as reflections on my role as a researcher and my emerging understandings of the politics at play through the research. These entries are included within the thesis as they have been important to mapping the research process and the unfolding of the study. My journal also served as an “audit trail” through which I could analyse my changing relationships with the group members and their changing relationships between themselves, with me and with their environment (McCabe & Holmes 2009; Koch & Harrington 1998).
4.4.1.6 Co-researcher field notes

Given the often hectic nature of the SCU, I encouraged ARG members to keep field notes of their observations, impressions and reflections throughout the study. During Stages One and Two, members brought with them occasional notes or accounts which they shared in the meetings. However, for the most part this activity was poorly taken up, which according to the members was due to their ‘lack of time’. It was not until Stage Three that some members more actively kept field notes as a way of documenting their observations about difficulties in being able to affect change in practice. These accounts included:

- Thoughts and reflection about the interventions;
- Problems and successes encountered when taking action; and
- Feedback from others about the interventions.

4.4.2 Other data collection strategies used in Stage One

In addition to the core data collection strategies reported above, other baseline data were collected during Stage one of the project.

4.4.2.1 Questionnaires

During Stage One of the project, the knowledge of all staff members on the SCU about dementia and a palliative approach was evaluated through the use of surveys. Three tools were administered to staff, (i) demographic questionnaire; (ii) Palliative Approach Quiz (PAQ); and (iii) Knowledge of Dementia Quiz (KDQ). The PAQ and KDQ needed to be developed from existing instruments, because on reviewing the literature it became evident that there were no tools that could be used directly in the context of this study. Given that the intention was to evaluate the relative knowledge of different staff members on the SCU, the tools that did exist to evaluate nursing staff knowledge, were not appropriate for the knowledge levels of PCA staff. Moreover, tools that looked at the principles of a palliative approach, rather than knowledge of more specialist palliative care were required. I also searched for a tool to evaluate staff knowledge about dementia generally, rather than specifically about Alzheimer’s disease, given that people within RACFs are likely to have varying causes of dementia (AIHW 2006). After an extensive review of the literature I located two tools that with modification would suit the needs of the study, these were: “Community attitudes to palliative care” tool (ADoHA 2003) and “Knowledge
of Alzheimer’s Test” (Maas & Swanson 2000). Permission was sought to modify and use the instruments. The development of the tools was an extensive and rigorous process that occurred across three stages:

a) Clarifying the conceptual domain and modification/generation;
b) Review of tools by an expert panel; and
c) Piloting of modified questionnaires and final modifications.

This development process is outlined in detail in Appendix 5 and the final questionnaires (demographic, PAQ and KDQ) are included in Appendix 6.

**Sample**

The demographic questionnaire, PAQ and KDQ were administered to staff working on the SCU who met the following inclusion criteria:

- At least 12 months experience in their current position and,
- Permanent part-time or full-time staff member.

These criteria were designed to capture staff members who consistently provided care for people on the SCU. Questionnaires were either distributed to staff during staff meetings or left in the nursing station at the end of the meetings for them to collect and complete. Staff members could either return their questionnaires to me in a sealed envelope or to a secure drop box at a different location within the facility, for collection by me.

**4.4.2.2 Resident documentation audit**

A second data collection strategy employed in Stage One of the project was an audit of resident documentation. The aim of the audit was to examine the degree to which a best practice palliative approach (ADoHA 2004) was reflected in documentation. A suitable audit tool could not be located within the literature. Thus, a tool and audit process were developed using a similar process to that described above for questionnaires. This process is detailed in Appendix 7 and the final audit tool is contained in Appendix 8.

The audit tool contained eight domains which were:

1. Advance care planning
2. Symptom Assessment and Management.
5. Spiritual Support for residents.
7. Review of care for the dying phase.
8. Bereavement support.

Key sources of resident documentation central in directing resident care were audited, these being the:

- Resident Health and Life Assessment (HLA);
- RCS documentation;
- care plan; and
- resident care daily notes and medical notes.

Time frames for the documentation audit were as follows:

- Daily nursing notes and medical notes were audited retrospectively across a time frame of 12 months, from the audit date. This time frame was chosen with the intention of providing a long-enough period to capture a spread of documentation about events and practices relevant to a palliative approach in the long-term care setting.
- Residents’ current care plans, admission documentation and most recent RCS assessment were also spot-audited.

Sample

A total of 21 resident files were audited. Of these, the files of 15 residents currently residing on the SCU were audited across the audit domains 1 to 5. This sample which accounted for approximately 40% of the SCU residents was considered to be adequate to develop a picture of how a palliative approach to care was reflected in the documentation. The files were randomly selected from those of the 35 permanent SCU residents and family caregivers who provided consent for the audit to be conducted and de-identified data collected. In addition, the notes from six residents who had died in the previous 12 months on the SCU were audited with respect to domains 6 to 8 to provide data on documentation related to end-of-life care. I audited all files manually. I conducted the audit on each resident file twice, checking for inconsistencies or omissions the second time. I recorded the data in hard copy and
entered it into Excel for analysis. A column for additional comments in the audit tool enabled me to record qualitative findings of interest such as repetitive phrases.

4.4.2.3 Semi-structured interviews

During Stage One of the study eight semi-structured interviews were conducted with family caregivers of residents in the SCU. These investigated how family caregivers understood dementia, the special care environment and the applicability of palliative care for residents. The use of a semi-structured format enabled particular topics to be explored while still allowing some flexibility to follow-up on other emerging areas of interest (Holloway & Wheeler 2002; Dearnley 2005). Semi-structured interviews have also been demonstrated as an effective approach to exploring sensitive issues (Birch & Miller 2000) and can provide the researcher with some visibility in the process so that the interaction is empathic. Hence, this approach was chosen as the most appropriate method of data collection with family caregivers.

The interview guide (see Appendix 9) was developed in consultation with ARG members and experts in my supervision team. Questions were specific to concerns that the ARG members wanted to explore further with family caregivers. I conducted all of the interviews. In practice, all participants were asked questions from the guide but in no defined order. All questions were open-ended, enabling participants to share their experiences; and subsequent questions were guided by their responses (Dearnley 2005; Hansen 2006). Probing questions were used to follow-up on important emerging themes. Interviews lasted approximately one hour, and were recorded and transcribed verbatim.

Sample and recruitment

A third party (allied health worker at the RACF), who did not provide direct care to SCU residents, approached family caregivers with a specific preamble about the project (see Appendix 10) to seek their participation in the interviews. Family caregivers were eligible to take part if the person with dementia for whom they were responsible had been a resident in the SCU for a minimum of 3 months. This was done to avoid causing undue distress, as research suggests the transfer of a person to a RACF can be a particularly stressful event for the resident as well as the family caregivers (Kellett 1999; Woods et al. 2008). If family members indicated to the third party recruiter that they were comfortable to be called by me I made contact with them and arranged a meeting at a convenient time and a location offsite to
protect their anonymity. During these meetings I provided an information sheet and consent form (see Appendix 10). The family caregiver then made contact with me if she or he wanted to participate in the study. A purposive sample of eight family members of residents with moderately advanced to severe dementia agreed to participate in semi-structured interviews during late 2006.

4.4.2.4 Critical dialogues

The perspectives of staff members on the SCU about palliative care and dementia were elicited through critical dialogues in Stage One of the study. In keeping with Lather (1991) these were interactive two-way engagements, structured more like discussions than traditional interviews. As with the ARG meetings, this approach was used to foster reciprocity between myself and the participants in the critical dialogue. During this process critical accounts about the provision of palliative care in the SCU from the ARG discussions were shared with participants to provoke their critical reflection on the issues. In keeping with Lather (1991, p.64), participants could verify and critique the ARG’s understandings, while also considering their own perceptions of and insights into the issues.

Sample and recruitment

Despite extensive recruitment efforts only four staff members from the SCU and two GPs agreed to participate in the critical dialogues. Five GPs who regularly visited the SCU received a written invitation to take part in the dialogues; one declined to participate, citing heavy workloads; two did not respond. Memos and information sheets were placed on the SCU and I conducted information sessions in an attempt to recruit staff members. Eligible staff members needed to have at least 12 months experience in their current position. Out of a total of 42 staff, four volunteered to participate (one EN, two PCAs and one allied health staff member). The GPs and SCU staff contacted me, at which point we arranged a time to meet, discuss the research and complete the consent form. During this initial meeting they were particularly concerned that their data not be shared with management of the RACF. These concerns perhaps reflected some of the problems in recruiting staff. Participants were reassured of their anonymity and the confidentiality of the research data. Data collection occurred at a location away from the RACF. The dialogues lasted for approximately one hour, were audio-recorded and transcribed verbatim.
4.4.3 Other data collection strategies used in Stage Three

During stage three, when the ARG members implemented a number of action plans, a variety of data collection strategies were employed to evaluate the outcomes of their interventions in practice. These included the use of various staff and family feedback forms as well as the analysis of documentation sources that were designed to be trialed in the implementation of the action plans. Chapters seven to nine report on these strategies as they emerged out of the iterative cycles of the action research process.

4.5 Data analysis

4.5.1 Qualitative data: first level thematic analysis

During Stage One, I subjected transcripts from the ARG meetings, family caregiver interviews and critical dialogues with SCU staff and GPs to a first-level thematic analysis (Hansen 2006; Ezzy 2002). Nvivo© qualitative software was used to assist with data management and analysis activities. Consistent with Hansen (2006), the analytic process of identifying, coding and categorising patterns emerging from the data was employed. Each transcript was read initially to gain a “sense of the whole” (Sandelowski 1995). Through closer examination, words and phrases were identified and grouped together to form emergent themes (Hansen 2006). Incidents or events emerging in the data were regularly compared with existing themes and this resulted in the themes further supported by the data being modified, or new themes being identified (Ezzy 2002, p.90). The analysis process involved repeated immersion in the data; reading and re-reading of the transcripts (Hansen 2006). Simultaneous collection and analysis/interpretation was in keeping with an iterative design (Ezzy 2002).

When analysing the ARG meeting transcripts, consistent with Kitzinger (1994, p.116) I paid detailed attention to the interactions between members during their discussions, as this provided indications of social processes “in the articulation of knowledge” and the operation of power relations between group members. Critical attention to the language used by members when telling their stories was also important, as it highlighted participants’ “priorities…and framework of understanding” (Kitzinger 1994, p.116). All meeting transcripts were developed into case notes and returned to members for their consideration and critical reflection.
4.5.2 Second level collaborative analysis of data by ARG members

Returning case notes and findings from the action cycles (after having undergone a first-level analysis) to ARG members was a strategy to promote critical reflection and collaborative data analysis. This process provided members with opportunities to tease out the particularities and everyday experiences that supported their underlying assumptions (Kitzinger 1994). Lather (1991) has pointed out that when doing research “with” people, co-construction and validation of meaning is central to ensure that issues reflect the lived experiences of practitioners. As a key methodological strategy, returning data to members facilitated their ownership of issues (Baldwin 2001; Lather 1991) and narratives emerging from their critical dialogues. These processes informed a growing critique of the ideological assumptions that shaped how members spoke about and understood their experiences of caring for people with dementia.

4.5.3 Quantitative data

Quantitative data from the staff questionnaires in Stage One (demographic questionnaire, PAQ, KDQ) were entered into Statistical Package for Social Sciences (SPSS) and descriptive statistics were generated. The frequency of the correct number of responses to the PAQ and KDQ were calculated and reported. For the purposes of analysis, respondents were divided into three groups, based on their educational and occupational backgrounds, these being:

- Nursing staff: registered and enrolled nurses;
- Direct care staff: PCAs and allied health (AH) assistants
- Service staff: cleaning and catering staff

Labelling the occupational groups this way was consistent with terminology used at the facility. Therefore, when these data was returned to ARG members, they were able to easily make sense of the findings and compare the knowledge of different categories of staff.

Data from the audit of the 21 resident files were entered into Microsoft Office Excel, 2007 and underwent descriptive analysis to determine the number of resident files that met the audit criteria. Qualitative information documented on the audit was mapped against respective audit criteria adding further clarification to some of the audit findings.
4.6 Validity in action research

In articulating validity claims underpinning action research, Hope and Waterman (2003, p.121) asserted that the “ethical and action-oriented principles” of action research were “validity enhancing”. Accordingly, judgements about validity should include considerations of power, participation, management of change and the relationship of these elements to reflection and the research process (Hope & Waterman, 2003; Waterman et al., 2001). In her post-positivist writings Lather (1991, pp.66-69) outlined validity criteria for praxis-oriented research as relating to face validity, construct validity, catalytic validity and triangulation. These concepts guided the development of validity in this study.

Firstly, intense participation between co-investigators and the researcher can enhance what Lather (1991) terms face validity. Research with face validity makes sense to those in the setting (Kemmis, S & McTaggart 2003, p.375) and “provides a ‘click of recognition’” in the response of participants. In this study, the ARG members were provided with access to all of the study data giving them an opportunity to offer feedback, modify or add to the issues raised. Their involvement in data analysis, the identification of concern, and the construction of action plans enhanced face validity throughout the project. Not dissimilar to Lather (1991), Reason and Bradbury (2001a, p.346) referred to the “quality of relational praxis”, as predicated on maximal participation of co-investigators, as an indicator of validity. Hence in the proceeding chapters the participation of the ARG members is detailed and discussed with respect to decision-making processes. The intention is to enable the reader to identify whether the account has relevance to their practice situation (Meyer et al. 1999/2000, p.43) and whether findings or “theoretical constructs” emerging from the study are “transferable” to similar settings (Koch & Kralik 2006, p.139).

The “dialectal movement” (Hope & Waterman 2003, p.125) between action and reflection, achieved through the action research cycle is a way of operationalising face validity. It enables co-researchers to deal with emerging issues (including ambiguities and contradictions) and iteratively refine theoretical concepts through critical analysis and informed action (Hope & Waterman 2003; Lather 1991). By engaging in the cyclical approach of action research a “premature foreclosure on data” can be avoided and reflexive engagement can be fostered (Hope & Waterman 2003, p.125). Reflexivity is achieved by investigators maintaining a self-critical attitude about their own preconceptions and how these may impact on the research
Reflexivity that is systematically adopted by researchers facilitates construct validity, because theoretical constructs emerge as a result of the research process rather than through the imposition of the researcher’s biases (Lather 1991, p.67). In this study, reflexivity was fostered by returning data to the research group for their analysis and encouraging them to keep field work journals. By keeping a research journal (Street 1990) myself, I was able to articulate some of my preconceptions and trace emerging theoretical understandings with ARG members. In turn, members had opportunities to verify, confirm or contest my ideas that I shared with them.

Lather (1991, p.66) argues that conceptual triangulation establishes “data trustworthiness”. Multiple data sources, collection methods and theoretical frameworks improves the quality of the data where both contradictions and consistencies can be distilled (Waterman et al. 2001; Lather 1991; Meyer 2000). In this project each data source was rigorously evaluated according to an appropriate “methodological criteria” (Street 2003, p.229). The different forms of data collected during the project linked conceptually to each other to present a “comprehensive account” of the phenomena under investigation (Street 2003, p.229). To this end both qualitative and qualitative data from multiple sources was triangulated. Street (2003) highlighted that the use of a variety of data collection methods allowed for the weaknesses of one method to be compensated by the strengths of another.

Finally, the nature and type of outcomes that are generated can also attest to the validity of the research. The achievement of outcomes that are both generated with and for participants and are also meaningful to others in their environment will provide an indication as to the quality of the catalytic validity of the research. Lather (1991, p.68) has contended that catalytic validity “represents the degree to which the research process re-orient,s focuses and energises participants towards knowing reality in order to transform it”. Within this study catalytic validity may be evidenced by changes in ARG members’ understandings and their actions to reconstruct aspects of their practice to better support an evidence-based palliative approach to care in the SCU.

### 4.7 Ethical considerations

Ethics approval for the conduct of this study was obtained from the Tasmanian Social Science Human Research Ethics Committee, University of Tasmania (H8633).
4.7.1 Informed consent

One ethical issue that is identified in the literature relevant to conducting action research projects relates to informed consent of participants. At the beginning of the project ARG members were given an information sheet and statement of informed consent. However, a number of authors Kelly & Simpson, 2001; Williamson & Prosser 2002; Meyer 1993) have highlighted that informed consent of ARG is not truly possible, as the change process is unknown and emerges as the research progresses. Meyer (1993) pointed out that consent may be based more on the willingness of people who participate and an initial acceptance at least of the researcher as a facilitator for change.

In Stage One of the project, research information sheets were provided and informed consent was obtained from staff members for their participation in the critical dialogues, and from family caregivers for their participation in the research interviews and for audit of resident’s notes. Implied consent was gained from staff members in the SCU who chose to complete the questionnaires. Extensive ethics amendments were submitted to the Tasmanian Social Science Human Research Ethics Committee about the conduct of the research interventions in during Stage Three. These ethics amendments detailed how ARG members would be responsible for distributing information sheets and obtaining consent from participants (e.g. family members, RACF staff) to be involved in the intervention. I outlined in numerous ethics amendments, that central to the ARG’s extensive involvement in developing intervention strategies was careful consideration of the range of ethical implications. Williamson and Prosser (2002) argued that “professional morality” and a continued awareness of this by staff in action research projects could promote appropriate and ethical behaviour for co-researchers in caring professions. Discussions about the ethics of voluntary participation, informed consent and the potential for participant distress formed an important and continuing thread during the ARG’s discussions and planning activities.

4.7.2 Confidentiality and anonymity

Another key ethical concern that faced me as an action researcher was to ensure that the ARG meetings were regarded by members as confidential. At the beginning of the research this was agreed between all members. The case notes were only accessible to members and they agreed that I would email the case notes to members as this would avoid the distribution of hard copies at the RACF. In the case notes and
this thesis, pseudonyms have been used to protect the anonymity of participants. Ethical data management was strictly adhered to and all data were stored in a locked filing cabinet in my office at a separate location from the RACF. However, given that the research meetings were held at a location at the RACF and that the ARG members were chiefly responsible for implementing the research interventions it was not possible to maintain their anonymity to their colleagues as the project progressed. Indeed, members became advocates of the project in order to gain support and encourage participation from their colleagues in the interventions. In the following chapters I have endeavoured to present the perspectives of RNs, ENs and PCAs in the ARG ethically and authentically.

In conclusion, this chapter has provided an overview of the demographic profile of the research field and characteristics of the research setting. Strategies for setting up the project and recruiting participants have been highlighted to emphasise that these preliminary activities were given careful consideration with respect to the methodological underpinning of a critical action research approach and the exigencies of the RAC environment. An overview of the structure of the study has been provided that illustrates how the ARG members shifted from a researcher facilitated engagement in the research process to a more proactive and critical stance. Data collection, analysis techniques and strategies to enhance the validity of the study findings have been discussed. Finally, key ethical concerns associated with conducting action research have been considered.
Stage 1: Preliminary Investigation: A Facilitated Engagement

Stage One of the study reports on the preliminary investigation undertaken with the ARG. This investigation comprised reconnaissance discussions between the ARG members and the collection of numerous other sources of data. During the reconnaissance discussions the ARG members shared stories about their practices during five one-hour meetings. Their narratives revealed a number of concerns about the provision of palliative care for residents on the SCU. To further explore these emerging issues the group embarked on the first action cycle, through which qualitative and quantitative data were collected to address the following:

1. Staff knowledge of dementia and a palliative approach (surveys);
2. How staff documentation reflected a palliative approach to care (audit);
3. Family caregiver’s needs and perspectives around dementia and palliative care (interviews); and
4. Perspectives of other stakeholders about palliative care and dementia (critical dialogues).

This stage represented a ‘facilitated engagement’ by the ARG members. Given their lack of previous experience with a research process, I was initially responsible for stimulating the group’s reconnaissance discussions and managed the data collection and first level analysis activities during Action Cycle 1. Through critical reflection on the data from the preliminary investigation, the ARG members began to see their situation “anew”, recognising the competing interests shaping their care practices. Findings from Stage One address the first research sub-question: Is a palliative approach to care reflected in the practices of aged care staff on the SCU and if so, how? and illuminates concerns about their capacity to support an evidence-based palliative approach to care.
Chapter Five: The Reconnaissance

5.1 Reconnaissance discussions

Five one-hour ARG meetings between April and July 2006 comprised the reconnaissance, largely facilitated by me. While group members were enthusiastic about discussing their practices (e.g., Anne (EN) stated at the first meeting ‘right let’s get down to business’), it was apparent that they had never previously met with the intention of solely discussing their practice. For example I noted in a journal entry:

After some initial reluctance on behalf of the ARG members and questioning and prompting by me, discussion between group members began to flow. ... It was obvious in the first meeting that despite working together on the same unit for a number of years, these staff members had few opportunities to engage in focused discussions about their practice. Indeed Judy (RN) confirmed this observation when she stated in the first reconnaissance meeting “we don’t get...discussion time” (Researcher journal April 13, 2006).

My facilitation of the discussions supported group members to share stories about practice and develop mutual understandings based in their personal/professional knowledge. Hence, the early ARG discussions comprised mostly descriptive accounts, about the complexity of providing care for residents and their family caregivers, as well as descriptions of competing tensions of workloads, documentation requirements and staffing issues. As the ARG members became increasingly comfortable to share their stories, they adopted a more critical orientation in their discussions.

5.2 Context of care

The research group’s initial discussions highlighted how a range of priorities shaped their practice in the SCU. Their narrative accounts explored how staff were constantly required to negotiate competing tensions related to the complex needs of residents and families, workloads and staffing concerns.
5.2.1 Complexity of Care: “behind the blue door”

5.2.1.1 Residents with advanced dementia

One of the first issues raised by group members was the unique nature of their practice environment in the SCU. In their opinion, the complexity of providing care to residents with advanced dementia and family caregivers positioned them in exceptional circumstances. Group members were emphatic that residents had a range of complex high-care needs including physical and behavioural concerns that often resulted in them having greater levels of dependency than other residents in the facility. Anne argued that residents ‘behind the blue door’ [entrance to the SCU], having impaired verbal communication, challenging behaviours and immobility, ‘are not normal everyday nursing home residents’ and that they ‘rely on staff’ to recognise, anticipate and meet their needs across a range of care domains.

The presence of concerning behavioural and psychological symptoms of dementia (BPSD) featured in group discussions as a key contributor to residents’ high care needs. For example, Judy highlighted that residents may behave in ‘intrusive’ and inappropriate ways. She described some of their behaviours as ‘horrendous’, recalling how one resident would ‘kick [and] punch’. Anne explained that in her experience residents were ‘disorientated to time, place and person’ and were less able to behave in ways that maintained their own safety. In respect to these behavioural difficulties, Anne noted that some residents were ‘a danger to themselves and … need more one-on-one [care]’, to ensure their safety.

Even though group members’ narratives highlighted the complexity of providing care for residents in the SCU, their discussions did not suggest an ongoing educative agenda at the facility to support staff. Rather, group members questioned the knowledge base of some staff, suggesting that they were in need of more education about dementia. For example, Heather raised concerns about some of the permanent staff routinely making comments to residents such as ‘I told you not to do that yesterday’ or ‘I told you ten minutes ago stop calling out’. Group members contended that such practices reflected a lack of basic understanding about the symptoms of dementia and effective management strategies.

The ARG members also raised concerns about the knowledge levels of casual or newly-hired carers working in the unit. For example, Anne explained that some of these staff lacked an understanding about the complexity of caring for people with
dementia, stating: ‘they think they are looking after little old men or a little old lady who will sit there and knit all day...’ There was agreement among members that providing care to residents was ‘demanding’. As discussions progressed, it was equally apparent that the needs of family caregivers also played a significant role in shaping the practices of SCU staff.

5.2.1.2 Family caregivers

Group narratives suggested that family caregivers often expressed multiple needs following their relative’s admission to the SCU and that staff had a key role in providing care and support for them. For example, Anne emphasised: ‘...part of the care [for the resident] is also caring for the relatives’. Group members asserted that this added a layer of complexity to care provision. According to their narratives, family caregivers often expressed a profound sense of grief and loss following the admission of their loved one to the SCU. Judy highlighted the multi-dimensional nature of this loss: ‘You’ve got to understand too that the family lose twice because of this disease [dementia]... to the resident not recognising them and then... to death [of the resident].’

Anne described one caregiver’s sense of grief, struggling with the loss of her mother and having to relinquish her primary care responsibilities: This lady was saying last night “Oh I’ve lost mum”, she said “... I’ve lost her going into a nursing home, I can’t do anything for her anymore” ...

Indeed for some family caregivers the ordeal of having a relative with dementia was just too painful. Heather explained this when she noted:

The thing that always amazes me working in aged care is the amount of families you don’t see... especially up there [on the SCU]... family caregivers will say “I don’t want to remember mum like that I want to remember her as she was, it upsets me too much”...

The ARG members also described some family caregivers as ‘vigilant observers’ of their relative’s appearance, of the behaviours of other residents and of care practices which occurred on the unit. For example, Elizabeth asserted the ‘family know exactly which staff have done (showered, dressed) mum or dad’. Members shared stories of feeling that they were under close surveillance by vigilant family caregivers, and suggested that family caregivers’ limited knowledge about dementia and specialised care practices in the SCU made their jobs much more complex and at times stressful.
For example, Elizabeth recalled how she had felt uncomfortable when being closely observed by a family member, when she was engaging in validation activities with a resident who believed that Elizabeth was her employer. Elizabeth recalled the family caregiver being disturbed by the interaction and explained:

*A relative was sitting [in the lounge room] watching me and I felt I was doing the wrong thing to [the] resident.... I had to explain [to the family caregiver] that [the resident] thought she was working for me.*

Group members emphasised that some family caregivers struggled to make sense of the care practices and the changes that they observed in their relative. For example, Anne stated that family caregivers asked questions like ‘*why isn’t Dad smiling anymore? Why isn’t he walking around?*. Judy pointed out that with limited understanding of the progression of dementia, often family caregivers ‘*don’t understand that residents lose the ability to do things*.’ In reference to this issue Elizabeth asserted that family caregivers often interpreted residents’ behaviours differently to staff and she noted: ‘*sometimes what we see as normal...the family don’t... they see it completely differently*.’ She also explained that without an accurate understanding of the unique care practices employed by staff in the unit, family caregivers were at risk of misunderstandings and distress. Elizabeth stated:

*...they [family caregivers] will see another resident sitting in a chair with a baby doll, and some people ...think that’s absolutely disgusting, how terrible ... [and] get offended...*

Catherine (PCA) explained that care practices such as doll therapy were structured on a premise that validates and respects the residents’ perspectives of their own world. Hence, she emphasised that staff ‘*live in the resident’s world*’ while working in the unit. However, group members held the view that with some family caregivers having little understanding of dementia and/or specialised care processes; this created challenges to establishing a dialogue with the family about their relative’s condition and care, which inevitably added to the complexity of care provision.

### 5.2.2 Resource availability

As ARG members shared their stories about the needs of residents with dementia and their family caregivers they also highlighted how a range of resourcing issues impacted on their capacity to provide quality care. Problems related to
5.2.2.1 Meeting documentation requirements

Documentation requirements were flagged by the ARG as a significant contributing factor to heavy work demands. The group’s stories highlighted how a considerable proportion of each shift was devoted to completing resident documentation in order to satisfy institutional requirements constructed around the RACF regulatory framework. Judy explained that nursing staff were required to fill out, on average, ‘40 pages’ of documentation each time a new resident was admitted. She stated ‘you can allow an hour and a half to two hours for each admission by the time you do all the paperwork’. On the whole, group members considered documentation as an imposition on their time, which could be better spent in providing care to residents. However, they also recognised that if documentation was not completed this could result in a loss of funding for the facility, a situation that would inevitably impact on unit staffing and their capacity to provide care.

In recognition of the competing consequence of documentation, the ARG members raised concerns about its usefulness. Judy asserted that there was an inherent ‘paradox’ in the documentation processes on the SCU, being that ‘a lot is written... but not much useful is said!’ Residents’ care plans were described as often lacking important, individualised information. Judy argued that care plans ‘are all repetitive’ and do little to inform staff about individual care strategies. Elizabeth agreed with this comment and suggested the obvious repetition of care-related information was apparent, because ‘just the names change’ on each of the resident care plans. In recognition of the perfunctory nature of the documentation, the group members were led to consider why care plans largely failed to contain useful and relevant information, specific to residents’ unique care needs.

Heather emphasised that care plans were constructed from existing documentation and therefore ‘... are only as good as the documentation that staff provide elsewhere in the notes’. These comments prompted the ARG to identify factors that impacted on the quality of their documentation. Their subsequent stories revealed that the use of generic language in their documentation was rife. While ARG members asserted that such methods were economical, they conceded the inherent limitations of this approach. For example, Catherine emphasised that important information about
resident care often ‘gets missed’. Reflective of a task-orientated approach to care, members highlighted how care practices were often, as Elizabeth stated, ‘taken for granted’ as ‘normal [and] routine’. As such she explained that the ‘little things’ staff do for residents may not be explicitly documented but rather, communicated usually through informal verbal exchanges. In recognition of the apparent contradictions of resident documentation, Judy stated that in her opinion it was ‘a waste of time’. Documentation requirements were a contentious issue for the group members. The dominance of this activity in their daily practice was considered to undermine the quality of care on the unit by exacerbating workloads and removing staff from direct resident care, with little benefit to staff in negotiating the complex care needs of residents and their families.

5.2.2.2 Managing within current staffing patterns

Staffing patterns were raised by the ARG as having significant implications for how their practices were constructed. Their stories revealed how recent reductions in staffing levels on day shifts in the SCU had resulted in challenging and hectic workloads. For example, Judy explained:

[care staff] are ... pushed because we had four eight-hour staff ... and one four-hour staff member [on a morning shift] ...since management cut us to 3.4 [three eight-hour staff members and one four-hour staff member]... it’s just got quite stressful.

According to ARG members the removal of an eight-hour PCA position meant that workloads were organised so that one PCA would be responsible for the care of ‘nine residents’. This staff-to-resident ratio was of significant concern to all members. Even more concerning was the reality that this ratio would increase to 12 residents per PCA if the unit was short-staffed. The regularity of short-staffing on the unit due to the difficulties in employing casual staff was evident at the fortnightly research meetings, where ARG members routinely made comments such as: ‘...we’ve been down 4 hours today’ and ‘...no 4-hours for the last 2 days’. As a result Catherine argued that workloads had ‘got heavier!’.

ARG members claimed that staffing on other units of the facility also inevitably increased their work demands; suggesting that SCU staff would be ‘targeted’ to compensate for a staffing shortfall elsewhere. This situation would typically consist of a PCA being relocated off the unit, or the RN/EN being required to work across an
additional unit. The group members argued that this change in skill mix reflected a lack of recognition by management of the complexity of providing care for people with advanced dementia. Elizabeth highlighted what she considered to be an attitude of indifference by management when she stated, ‘they [management] just think oh we’ll cope, we’ll get through…and we just can’t!’ Under these conditions Judy explained that family caregivers who visit the unit ‘recognise that staff are running around and that we haven’t got time’. From this perspective she suggested it was perhaps understandable that family caregivers adopted ‘vigilant’ roles.

5.2.3 Dealing with skill mix and GP accessibility

The presence of casual PCA staff in the SCU was another cause for concern related to increased workloads. ARG members described the perceptions of these staff, who may have spent limited time in a dementia-specific environment, as somewhat problematic. For example, Elizabeth recalled how casual staff had previously implied that working in the SCU was equivalent to having a ‘holiday’; indicating that the needs of residents were not as demanding as those on other units.

ARG members postulated that such misconceptions on the part of casual staff were related to inexperience and unfamiliarity with residents, as well as deficits in these staff members’ knowledge about the needs of people with advanced dementia. Consequently, members explained that they felt compelled to instruct casual staff about appropriate care practices/management strategies for residents, which they suggested increased their workloads.

The lack of accessibility to GPs was also identified by nursing staff in the ARG as a key contributor to increased workloads, and an issue which further exacerbated existing problems with skill mix. GPs were described by nurses within the group as ‘overworked’ and as such, Judy suggested that ‘GPs agree to take residents on but then...resent having to leave their practice...to come to the unit to visit them’. Consultations were described by one of the RNs as ‘ten minutes with the resident, do what you’ve got to do and out again’. Nursing staff explained that under these circumstances they had limited opportunity to engage with doctors and often had difficulty getting them to make timely visits. It was suggested that this situation was further exacerbated when residents were required to change GPs following relocation to the SCU. Heather stated that in these circumstances residents ‘get what doctors are happy to come and visit them’; however this meant that they were often
unfamiliar with residents and their medical background, which she stated created a ‘huge problem’ in maintaining continuity of care. Judy indicated that she was regularly required to ‘chase up’ doctors to discuss care issues and ensure that tasks such as medication orders and prescriptions were completed. These circumstances were highlighted by nursing staff as placing additional demands on their time. Generally, ARG members did not convey a sense of partnership with GPs; rather, through their narratives staff suggested the presence of fragmented relations and a lack of confidence in the support from these professionals.

The narratives of the ARG suggest that insufficient resourcing in the SCU had a range of implications for the capacity of staff to provide individualised, person-centred care. The above accounts highlight the tension between care requirements of people with advanced dementia and resource availability within this aged care environment.

5.3 Implications for care provision in the SCU

Through sharing their stories, the ARG members progressively embraced a more collaborative agenda. As they considered how the context of care on the SCU impacted on the provision of care for both residents and family caregivers, key issues were revealed with respect to end-of-life care, pain management, and the capacity of staff to support residents’ family caregivers.

5.3.1 Impact of the care context on resident care provision

The ARG narratives suggested that the quality of resident care was severely undermined by heavy workloads and staffing issues. For example, Catherine explained that in order to meet heavy work demands, her practice was essentially task-orientated and routine-based. She described it as ‘repetitive’ and ‘remote control’. Elizabeth argued that ‘there is no time for one-on-one care’. In recognition of this concern, Catherine agreed and stated that at best ‘you might catch [a resident] as they are wandering past you to have a chat’. In response to these accounts of practice, Judy described person-centred care as ‘a joke’ within the reality of day-to-day practice.

Through the emerging narratives of the group it was revealed that in order to negotiate heavy workloads, especially during periods of short-staffing, ‘shortcuts’ were taken when attending to routine resident care tasks. While Catherine recognised that this situation was ‘not very satisfactory’, she reluctantly acknowledged that in
order to adhere to a ‘time schedule’ and meet work demands, ‘you...have to skip things, so you take the shortest way out’. Woven throughout the ARG members’ stories were numerous examples of the usual shortcuts that were taken in practice. For instance Elizabeth stated:

... like the last few weeks ... we haven’t got to do any toileting after lunch and we used to always toilet [Residents] straight from the dining room ... we haven’t been able to do it because we’ve still had residents to [provide care for].

Catherine explained how some residents, who were at risk of sustaining a fall if left unsupervised, would be physically restrained at busy times during the day. She stated ‘we’ve got restraints, we can’t watch them, they are left out in the lounge room when we are doing care work’. Moreover, Anne highlighted how some bed-bound residents may not have their care needs met until well into the afternoon, as such ‘laying [sic] in bed all night and all day’ if the unit was short-staffed. In recognition of such circumstances Judy summed up the impact of heavy workloads on resident care as ‘horrendous’ and highlighted that some of these situations did not escape the watchful eyes of some family caregivers and indeed reinforced their desire to be even more vigilant.

Care staff in the ARG emphasised how short-staffing and heavy workloads had a profound impact on their capacity to provide dignified, comfort-orientated care to dying residents. For example Catherine stated:

...[staffing impacts] greatly; we can’t be with the [dying] resident, quite often when we are short-staffed we don’t have time and we just don’t get back to them, so they are left lying there...they are just left there in the beds until we can get back to them...and sometimes we don’t...cause you are so flat out looking after the others.

Catherine and Elizabeth, both PCAs, highlighted the importance of ‘being there’ with the resident during the dying process and doing ‘little things’ to comfort the person. However, their narratives also indicated that they were often frustrated in their efforts to achieve these goals, as Catherine explained in the following account:
When we had a spate of running short [-staffed], we had a few [residents] dying and they were left. I mean they got the best care we could give them but it wasn’t enough I don’t think.

After reflecting on Catherine’s comments, Elizabeth agreed that the care provided to dying residents is often ‘too rushed’ and not of a sufficient standard. Overall, the ARG’s narratives suggested that, due to resourcing inadequacies in the SCU and increasingly complex care, task-oriented care and taking shortcuts had become an established part of practice. However, there was a resounding opinion amongst ARG members that this could not be considered ‘good practice’ but rather the best that could be done under then-current workplace conditions. For example, Judy stated ‘it’s not the way you want to work...you want to do [more], you want to have more time...’ In contrast, Anne recalled experiences of working at the RACF in previous times when there was better staffing regimes and care was not as complex. She stated:

*I can remember working... having a fantastic time...it might have been a production line, but they were all showered by 10:30...and there was always a plan of what staff would be doing with ... residents for the rest of the day. Two would take a group walking around the park, around the gardens, two would be doing hair...it is where job satisfaction came in...Now this is where [job satisfaction] is lacking...*

Other ARG members indicated that their current practice was professionally dissatisfying and disempowering. Elizabeth’s comment suggests the unsustainable nature of the care environment, ‘You do go home feeling guilty, feeling that you haven’t done what you’ve set out to do...the thing is, physically and mentally we can’t [cope]!’.

The maintenance of effective pain management for residents was also raised by the ARG as a significant problem associated with staffing issues on the SCU. Elizabeth explained how the presence of casual nursing staff on the unit often resulted in residents not having their pain adequately managed. She recounted:

*You come back after 5 days off and somebody is in pain and you look back through the daily organiser and there has been different trained staff each day, so that’s why you know [residents] are not getting [PRN pain medication].*
Similarly, Catherine argued that pain management ‘seems to be at its worst’ during periods of high turnover of casual staff unfamiliar with the residents. Indeed ARG members argued that relying on casual staff to recognise a resident in discomfort and administer analgesia was often problematic; as it usually required intimate knowledge of the residents and his/her behaviour. Without this level of familiarity, members explained that casual staff were less likely to detect the presence of pain. Anne recounted:

...for 3 or 4 weeks now the resident had been having QID Panamax\(^2\) (analgesia) or TDS, either or, it’s a PRN order. Last week ..., no-one (casual staff) actually gave the PRN medication to him, so every day until...when I came back no-one had given him [medication].

As a further complicating factor, members also highlighted that there was ad hoc approaches to pain assessment for residents in the SCU. Anne explained that if analgesia was being administered to a resident, even on an ‘as necessary’ basis, it was not unusual for nursing staff to administer the medication without assessing the resident. She explained that a recent entry for analgesia on the resident’s drug chart functioned as a cue for nursing staff to re-administer the medication. Anne argued that this system of medication administration was flawed, but surprisingly not with respect to absence of an adequate pain assessment. Rather, she explained that at the beginning of each month a new drug chart was commenced, which meant that the record of analgesic administration for the previous month was removed and filed. As a result, she recalled a resident requiring regular PRN analgesia who was not administered it on the first of the month or for five subsequent days until at which point he started to display obvious symptoms of pain and discomfort.

Finally, ARG members highlighted problems with the accessibility of GPs in relation to effective symptom management and continuity of care. For example, Heather explained that not being able to access a resident’s GP in a timely manner had significant implications for the co-ordination of end-stage care. She stated:

...being so far away from the GP and then just trying to get things organised for a symptom that has just suddenly come on, sometimes that’s a little bit tricky…See I needed some Midazolam for a lady the other night…by the time

\(^2\) Also known as Paracetamol (acetaminophen). It is simple analgesic with anti-pyretic properties(Therapeutic Guidelines 2005).
Moreover, GP accessibility was also considered by members as a key factor that impacted on their capacity to provide care for residents in their familiar surroundings, especially when they were dying. For example Heather explained:

...you just have a condition on the unit that you just can’t deal with, there is not a Doctor on call ...if you want some Lasix or something ... you’ve still got to get an order for it, and if you can’t talk to the GP concerned then you’ve got to talk to the after-hours GP and...they don’t know the scenario... they’ve got to get in touch with the original GP and then... it all might be too late, things have escalated and you’ve got to get the person out [to hospital].

The implications of the above scenario being that a resident is transferred to an emergency department which as Heather explained may be ‘bogged under’ and they are subjected to a ‘three or four hour wait’ before being assessed. This type of management caused a great deal of angst among the group members who held a strong conviction that dying residents should be able to remain in familiar surroundings without having to undergo the disruption of being moved and the inadequate care processes that often accompanied this.

5.3.2 Capacity of staff to support family caregivers

With ARG members having recognised the complex needs of family as shaping their practice, resourcing issues were identified as restricting their capacity to provide support and establish partnerships with family caregivers, consistent with a palliative approach to care.

Nurses in the ARG explained that they were frequently faced with a shortage of time as a result of chronic staff shortages and challenging workloads. As such, they recognised that their capacity to provide emotional support to family caregivers was undermined by these competing demands. In the following account, Anne highlights the dilemma of spending time with family caregivers who require support, while attempting to negotiate heavy workloads. She stated:

...we’ve got a new resident and...her daughter is really grieving at the moment. I spent about half an hour on Monday night with her on the
...I’m trying to get off the phone, knowing that I had to be down on [another unit]...and this is it, you just don’t have the time.

Judy also reported a similar tension in her practice:

They [family caregivers] are seeking out people to talk to...I’ve got to watch myself on a Monday morning, ’cause Mondays are always hectic and I seem to be caught with this lady [a family caregiver] every Monday morning and she doesn’t look like she wants to move from the office and I’m thinking, ‘hey I’ve got a lot of work to do today’...

The potential consequences of this situation were further highlighted by Anne when she explained that information given to family caregivers on issues related to dementia or their relatives’ care was predominately provided in an informal and reactive manner. She stated:

...[the new resident’s family caregiver] said, ‘oh mum wanders of a night, I’m really worried that mum will wander of a night’, and I explained to her, that this is the whole reason, this unit is designed for people who wander, I said ‘don’t worry she’ll be one of six that will be up wandering’... that is what they need to know that this is normal.

Consistent with ARG members’ emerging understandings that their interactions with family caregivers were structured in reactive ways, Judy argued that there was not enough time in her day to provide family caregivers with information about dementia in a more formal or rigorous manner.

Reflective of the competing tensions that shaped ARG members’ practices, their accounts suggested that there was a relative absence of partnership between staff and family caregivers in the SCU. The implications of these circumstances were evident in a comment by Judy who described her experiences of interacting with family caregivers as akin to being ‘on pins and needles’. Amid these competing conditions Judy reflected that interactions with ‘difficult’ family caregivers who were considered by the staff as ‘anxious and not coping’ were largely avoided in order to minimise the intrusion of those family members on staff time.

5.4 Palliative care in the aged care environment

ARG members discussed at great length the above issues that framed the context of care in the SCU. However, given the focus of the project on exploring the
possibilities for developing staff practices around a palliative approach to care, members’ discussions shifted to how they conceptualised palliative care in the SCU. From their stories it was evident that they could articulate most of the key principles underpinning a palliative approach to care. For example, members agreed that palliative care was a core component within their practice and that ‘elements’ of palliative care were integrated ‘along the way’, during the process of care, ‘long before’ residents made the transition to ‘end stage’. There was also agreement that palliative care was ‘individualised’ and a person-specific approach. Moreover, members considered that SCU staff had generally a ‘good’ level of knowledge about palliative care. On further questioning by me about what constituted a good level of knowledge, Judy explained that staff on the SCU understood palliative care as “all about comfort”, largely as a result of participation in education sessions held at the RACF. Members were however unable to provide further detail about the knowledge base of their colleagues.

When I asked ARG members if there were any barriers to being able to provide palliative care to residents, they indicated that there were no significant issues of concern. With respect to this I documented in my journal:

> Basically, in yesterday’s meeting the group agreed that they do palliative care “really well” and that there are “no major issues”. I was surprised by this to say the least (Researcher Journal July 5, 2006).

As evident in the above journal account I was somewhat perplexed by the ARG’s response, given their earlier discussions about contextual factors that impacted on their capacity to provide care in general. However, as the ARG came to more closely interrogate how a palliative approach to care was reflected in their daily practice in the SCU, it became apparent that their conceptions about palliative care were somewhat rhetorical. Firstly, members encountered difficulty delineating when a palliative approach should actually be initiated for residents. Indeed the majority of discussions suggested that the administration of analgesia was synonymous with a shift into a palliative modality of care. Anne highlighted this when she stated: ‘you do need to start off with Panamax in a palliative approach I feel’.

During the ARG’s efforts to disaggregate how and when their practice reflected a palliative approach, Judy explained that a resident may ‘present differently’ or be ‘more resistive than normal’ and that these observations, usually made by the care
staff, were informally communicated to the RN/EN on the shift. Judy explained that based on such information analgesia would be commenced accordingly, usually in the absence of any type of formal symptom assessment. Despite the apparent absence of a more rigorous approach to resident assessment, the administration of analgesia was frequently described by Anne and Judy as the ‘starting point’ in the provision of palliative care. The presence of specific indicators marking a decline in a resident’s health status was also identified as marking a shift in care towards a palliative focus. Heather shared stories that illustrated this point, for example she suggested:

> It’s when you have those sort of big “clunks” like… that person has stopped mobilising ... they are difficult to feed now, and that sort of gives you a good indication ... that’s a stepping-off point...

Contrary to the ARG’s previous claims indicating palliative care was initiated early on in a resident’s stay in the SCU, their subsequent stories suggested that an obvious change in a resident’s condition provided the necessary impetus for staff to consider issues related to palliative care. In the above excerpt Heather’s reference to ‘big clunks’ was indicative of changes that usually reflected the resident’s transition into an end-of-life phase. Similarly, Anne explained that her care practices would most likely have a palliative focus ‘when you get to a point where you think “right, there is no return”’. Members reported that administering of non-essential medications usually ceased in these circumstances, and measures to ensure a resident was ‘comfortable’ were paramount.

As ARG members critically reflected on their discussions (facilitated by reviewing the meeting case notes) they became increasingly aware of the contradictions in their stories; between the way in which they conceptualised palliative care and how it was actualised in practice. On one hand, members described palliative care as starting early in residents’ care, while on the other hand their descriptions of practice revealed quite the opposite - that palliative care was not usually initiated until end-stage. On recognition of this dissonance, members were provoked to further interrogate their stories of practice. Through their critical reflection emerged an awareness among ARG members that aged care was underpinned by a philosophy that focused on the promotion and maintenance of residents’ physical functioning and social engagement. The group members reflected on how this ethos shaped the way that staff understood and constructed their practice. For example, Heather stated that people ‘don’t just come [into a nursing home]...and do absolutely nothing...you
go out on outings...and we organise [activities]...and you enjoy life’. Anne noted that in practice there was an emphasis on ‘trying to rehabilitate’ residents to promote their levels of physical and social functioning. Judy agreed with this position and commented that maintaining residents’ independence ‘is in your job description’. The discussion on this point was lively, reflecting a range of assumptions that underpinned how the group members conceptualised their care practices. The contradiction experienced by group between keeping residents active, while at the same time providing palliative care was perhaps best exemplified when Anne stated, ‘residents have come here to live...they haven’t come here to die! ...you just want to make the nursing home their home not a death trap!’ The ARG members struggled to imagine how, amidst such contradiction, they could develop their practice around a palliative approach to care.

5.4.1 Preparedness of staff to talk about death and dying

The stories shared by the group members revealed that the intersection between aged care and palliative care philosophies was problematic for them. Reflecting on this dissonance they recognised that their understandings were in part influenced by their negative perceptions about death and dying. Through their narratives, the group members revealed that talking about such sensitive issues (with residents, families or between staff) was not an established or accepted part of practice. Anne argued that staff members were generally ‘reluctant’ to initiate discussions, because as she explained ‘talking about death is ...an anti-social thing’. In response, Catherine claimed that staff were ‘all programmed for slow deterioration’ and therefore she argued that residents’ deaths were ‘just part of our work ... and it just follows suit’. It was evident that dealing with death in the SCU was a taken-for-granted aspect of practice for the staff members and proactive discussions about death and dying were rarely pursued. Judy explained the implications for communication with family caregivers when she stated that nursing staff ‘pussy foot’ around the topic of death and dying. However, Anne raised concerns about her capacity and that of other staff to facilitate such sensitive conversations when she stated: ‘How do you go up to someone and say, “oh I think your Dad is going to die soon”, or talk about death?’

The unpredictable progression of dementia was raised by group members as contributing to the reluctance that staff felt in initiating discussions about death and palliative care with family caregivers. For example, Heather revealed that staff were more willing to discuss issues related to death and deterioration when residents had
conditions with a more defined dying trajectory ‘like an existing cancer or COPD’. However, that the subtle and often unpredictable deterioration of residents with dementia appeared to serve as a deterrent to initiating such discussions with family caregivers was evident in numerous stories shared by the ARG members. For example Anne stated:

... if someone came in with COPD you know what is going to happen to them as they get further and further...right this guy is going to have these sort of problems as he gets to end-stage...but if someone comes in with just dementia and that’s it, well it would be hard to plan then ...

Judy highlighted the implications of staff members’ reluctance to initiate communication with family caregivers about a resident’s disease progression and associated care needs when she explained that such discussions occurred at ‘late stage’. Judy described that such meetings often occurred opportunistically, for example, at instances when family members were in the SCU at the same time as a doctor or at a point when it was necessary to contact family caregivers to inform them of a resident’s deterioration and impending death.

5.4.2 Awareness of the Palliative Approach Guidelines

Interestingly, at no point during the reconnaissance discussions did any of the ARG members refer to the Guidelines (ADoHA 2006). During discussions when the group explored how palliative care was operationalised in the aged care setting, I deliberately did not ask them about their knowledge or awareness of the Guidelines. Rather, I decided to observe whether discussion about the Guidelines emerged unprompted by me. By the time of the final reconnaissance meeting in July 2007, I was intrigued as to why this topic had not arisen given the relevance of the Guidelines to the group’s discussions and the project as a whole. I captured this issue in the following journal account:

When I asked the group members about their knowledge of the Guidelines in today’s meeting a poverty of discussion ensued. It was at this point that it became clear why there had been a lack of reference to the Guidelines throughout our earlier meetings. With the exception of Heather, the members of the ARG were unaware of the existence of the Guidelines! (For that matter they were also unaware of the existence of the recently released “standards for pain management in RACFs” (Researcher Journal, 18/07/06).
The ARG members had signposted a number of areas requiring further exploration throughout their reconnaissance discussions. Consistent with observations of Kemmis and McTaggart (1988, p.64), the reconnaissance data contained ideas about what needed to be done next. Having raised a broad range of priorities and politics that shaped their practices, group members agreed that before they could investigate strategies to improve their practices they needed to develop a more comprehensive understanding of their situation. Group members recognised that their key concerns lay with exploring the following areas:

- staff understandings of palliative care and dementia;
- whether staff practices, including resident documentation, reflected a palliative approach to care; and
- the needs of family caregivers in the SCU and capacity of staff to support family caregivers.

5.5 Discussion

The reconnaissance discussions provided opportunities for the ARG members to meet and share their stories about caring for people with dementia and their family members. These staff members had never previously come together solely with the intention of discussing their day-to-day practice and their enthusiasm to do so highlighted their isolation from each other, despite being physically located within the same facility and indeed in the same unit. Similar concerns about the isolation of aged care staff are evident in the literature (Jones & Cheek 2003; Jones et al. 2002; Venturato et al. 2006). In research published after the completion of this study, aged care staff identified feeling professionally disengaged from their colleagues, with little opportunity to share their concerns about practice (Wilkinson et al. 2009). Through the reconnaissance discussions the ARG members discovered that they shared mutual concerns, prompting them to dialogically explore these issues. From a Habermasian (1996) perspective the establishment of shared dialogue around mutual concerns can be understood as the ARG members opened up a communicative space.

Initially, group discussions focused on the challenges associated with meeting the needs of people with dementia and their family members. Accounts about managing behavioural disturbances, anticipating the needs of non-verbal residents and ensuring resident safety, were findings highly consistent with the literature (Wowchuk et al. 2006). Research (Chang et al. 2009) published after the completion of this study, that
reported on focus groups and interviews with RACF staff (n=18) and other key professionals (n=27), emphasised that the complexity of caring for people with dementia was a key challenge for all staff. Moreover, the accounts of the ARG members, similar to reports in other aged care literature (Venturato et al. 2006; Angus & Nay 2003; Phillips et al. 2006; Jones et al. 2002; Wowchuk et al. 2007) illustrated that this complexity was heightened by conditions of staff rationing, short-staffing, the inaccessibility of GPs and regulatory requirements.

The group members’ stories about caring for residents with advanced dementia suggested that their practices were structured around ritualised, task-oriented approaches to care, rather than evidence-based practice. These findings are supported in research (Allen et al. 2008; Kayser-Jones et al. 2003; Miskella & Avis 1998; Tuckett 2005) that has highlighted the persistence of routine, physical care provision at the relative expense of psycho-social aspects of care (Ballard et al. 2001; Wilkinson et al. 2009). The PCAs in the ARG shared stories detailing how they struggled to meet some of the basic care needs of residents due to the impacts of short-staffing. Their narratives revealed that taking ‘shortcuts’ during resident care tasks was a commonly employed strategy to negotiate heavy workloads. This finding is notable because little research has previously explored the dynamics of PCAs’ practice in Australian RACFs (Chandler 2003). The narratives about resident care being organised around the allocation of tasks in this study resonates with the findings of Miskella and Avis (1998 p.82) who have suggested that “senile” elderly are “processed” in nursing homes with little individualised care.

With respect to the above findings, Habermas’ (1987a) theory of system and lifeworld provides a way of understanding how organisational imperatives shaped care practices of staff in ways that were reactive and depersonalised. The group’s narratives of systematic rationing of resources is reflective of what Habermas (1987a) has referred to as ‘systems functioning’. Here, the privileging of resident documentation and task-based care meant that care practices (in the lifeworld) were similar to what Tuckett (2005, p.220) described as a “production line” model – where efficiency and outputs are highly valued. In their support of an instrumental care culture, the group’s narratives suggested that their actions were necessarily oriented towards “doing” of physical tasks. Hence, the notion of person-centred care (Kitwood 1997) was described by one of the group members as ‘a joke’. These findings highlight how the systems world “strategically imposes expectations”
for efficiency on aged care staff which in turn shapes their experiences and ways of acting in the lifeworld.

The ARG members’ stories about repetitive documentation patterns and the construction of perfunctory resident care plans further highlight the imposition of system world imperatives. Consistent with the observations of Jeong and McMillan (2003), the group members conceived documentation as a task that they ‘must’ do, to satisfy aged care regulatory requirements and resource-focused institutional interests. However, the rhetoric associated with documentation requirements in RACFs, was evident when the ARG members highlighted what they considered the ‘paradox’ inherent in completing multitudes of resident documentation, with little positive impact on the quality of resident care. Consistent with these findings Venturato, Kellett and Windsor (2007, p.9) have reported that the increasing responsibilities of nursing staff in particular, around documentation and other “management-related” activities, has meant that they struggle to take accounts of “resident-focused” needs. Yet, while group members deplored the usefulness of documentation, at the same time they acknowledged its necessity for continued functioning of the organisation. Such insights reveal that dominance of “economic rationalist” agendas (Angus & Nay 2003) that impact on the practices of staff in the sector.

It was apparent from the narratives of the ARG members that they held a number of assumptions about what “must” be done to satisfy organisational and regulatory interests, as opposed to what “should” be done to promote the quality of resident care (Bowers et al. 2001). These findings reveal how SCU staff operated in a network of hegemonic power relations, characterised by privileging institutional/organisational interests. The stories shared by ARG members illustrated what they imagined to be the inevitability and necessity of procedural, task-oriented care and repetitive documentation practices. In this sense, the hegemony of institutional interests was sustained by staff members’ unexamined practices that supported system imperatives. These findings highlight how, commonsense understandings and taken-for-granted practices become institutionalised through what Turner (1997, p.xii) has referred to as the operation of power through “every day routines and mundane arrangements”. Having little insight into their own implication in this hegemony the ARG members reported a sense of powerlessness and professional dissatisfaction; consistent with the findings of others (Jones et al. 2002; Moyle et al. 2003). Similar to findings reported by Street (1992, p.224), and reflective of the group’s
enculturation into an instrumental care culture, the ARG members maintained care rituals that were inimical to their own professional/personal lives as well as the lives of residents.

By sharing stories and having the opportunity to reflect on them, the ARG members came to recognise that the care they were providing to residents was contrary to that which they aspired. These insights revealed the implications of what Kemmis (2001, p.97) has referred to as “boundary crises”, or “collisions” between system world imperatives and lifeworld aspirations. Group members revealed desires to practice in ways that supported lifeworld processes - whereby residents with dementia could be respected as individuals with unique identities and needs, through what has been identified in the literature as “person-centred care” (Kitwood 1993b, 1997). Yet the narratives of the ARG members suggested that they felt powerless to construct their practices differently from the instrumental approaches that they had historically and unquestioningly adopted. These findings reflected how group members were “stuck” in a reactive space, where, as described by Comstock (1982, p.384), “ideologically frozen understandings” limited how they understood their actual circumstances and future possibilities. In addition to the ARG members’ emerging awareness of the dissonance between the care they wanted to provide and the care they did provide to residents, a similar dissonance was also evident in their narratives about family caregivers.

The ARG members were able to identify and vividly describe the often difficult and challenging lifeworld experiences of family caregivers. In particular, and consistent with the findings of others (Gessert et al. 2001; Forbes et al. 2000), they suggested that family caregivers’ limited understandings of dementia and the SCU impacted on their capacity to cope with changes in residents’ condition and their care. Moreover, in keeping with the literature (Kellett 1998; Kellett 2000, 1999; Garity, 2006; Aneshensel et al. 1995) the ARG members reported that family caregivers experienced grief and guilt associated with their relatives’ conditions and location of care. However, despite their insights into some of the distressing experiences and multi-dimensional needs of family caregivers, the group’s narratives suggested that they struggled to accommodate these needs, which in the context of a highly-routinised day took considerable time.

The work of Small and colleagues (2007) is illuminative with respect to this finding, as they have highlighted that the lifeworld experiences of people such as family
caregivers may be at odds with the system world imperatives (p.97) that structure how care is provided. Indeed, the implications of these circumstances were apparent when group members reported taking action to minimise the intrusion of family caregivers on their time and routines, which in some instances meant avoiding interaction altogether. Similar findings have been reported elsewhere (Bauer 2006). The ARG members unwittingly exercised power to ensure that their routines sustained minimal disruption. The operation of power relations in this manner is particularly problematic given that research suggests (Kelley et al. 1999; Mahoney 2003) family caregivers will often take on more vigilant monitoring roles when they feel that their relatives’ needs are not being met and/or when their concerns are not being listened to. Clearly, the desire of staff members to provide ‘efficient’ care delivery, thereby supporting hegemonic interests of the organisation, conflicted with the needs of family caregivers to be heard, given information, be provided with emotionally-sensitive care and included as valuable members of the care team (Albinsson & Strang 2003, 2002; Kellett 2000; Woods et al. 2008). Rather, the ARG members concerns centred around the contribution of family caregivers to compounding the complexity of their work, overshadowing any recognition of their positive contributions to care that have been so well documented (Woods et al. 2008; Davies & Nolan 2006; Haesler et al. 2006).

It is interesting to note that more recently the problematic nature of “routine care” has been questioned in the literature (Zisberg et al. 2007; Bouisson & Swendsen 2003). When examining this point with respect to the construction of interpersonal relationships between aged care staff and family, Brown Wilson and colleagues (2009, p.1056) contend “the issue becomes not whether ‘routines’ are good or bad, but how they can be personalised and used to enhance relationships and quality of care”. However, the historic privileging of unexamined routines that supported what Tuckett (2005, p. 220) has described as an “instrumental” culture of care, limited the ability of the ARG members to recognise opportunities where they could adopt a personalised approach to care. The findings of this study support existing work (Davies et al. 2007; Nolan et al. 2004; Nolan et al. 2006) that highlights the importance of cultural change in long-term care settings so that positive, collaborative relationships between staff, family caregivers and residents can be nurtured.
As the ARG members progressively exposed the implications of contextual and system factors on care provision for residents and family, their discussions extended to interrogate the provision of palliative care. Reflective of their emerging critical engagement, the group members recognised that their understandings about the provision of palliative care were more rhetoric than reality. As reported in other research (Clare & De Bellis 1997; Maddocks et al. 1996; Phillips et al. 2008; Travis et al. 2002) palliative care was operationalised in a reactive manner, usually initiated in response to an obvious deterioration in a resident’s condition that was indicative of an end-of-life phase. Moreover, none of the ARG members overtly acknowledged dementia as a terminal condition, a finding also present in the literature (Kaasalainen et al. 2007). The reflections of the group members can be understood as “partial penetrations” (Willis 1997 in Lather 1991, p.63) into the dissonance between their espoused theories of palliative care and their actual practice. Group members explored the implications of aged care as a “point of entry” (Willis 1997 in Lather 1991, p.63) for them to interrogate broader cultural conditions that shaped their practice around a rehabilitative culture, whereby the maintenance of physical functioning and social engagement was prioritised.

The rehabilitative/restorative culture of aged care has been previously acknowledged in the literature (O’Connor & Pearson 2004; Engle 1998; Abbey 1994; O’Connor 2009). Froggatt (2000a, p.15) reported that in UK nursing homes the attainment of a “normal life” is a highly-valued goal. However, the propensity for “normalisation” in RAC has obscured the recognition of the needs of people with progressive and debilitating conditions such as dementia (Angus & Nay 2003; Abbey et al. 2006; O’Connor 2009). Stories shared by the group members, which suggested maintaining residents’ independence was integral to their roles, reflected how the ethos of normalisation was a taken-for-granted assumption dictating care provision. Consistent with the literature (Street, Love & Blackford 2005) and reflecting the pervasiveness of this taken-for-granted understandings, the ARG members emphatically described RACFs as places where people “live”, rather than where people “die”. This finding is concerning given that RACFs are increasingly recognised as locations where death and dying is commonplace (Teno 2003; Andrews-Hall et al. 2007; Komaromy 2000), a point also acknowledged by the ARG. These findings suggest that a fundamental challenge to implementing a palliative approach to care in RACFs is the dichotomy associated with “living” in a RACF as opposed to “dying” in one.
The reluctance of the ARG members to talk about issues of dying suggests that while it may be a familiar event for SCU staff, it is largely unacknowledged in routine, everyday practice. The narratives of group members, which supported the perspective that discussions about dying and death were ‘anti-social’ can be understood as reflecting what Gramsci (1971) would refer to as “common sense”. Arguably, such assumptions emerge from a broader cultural anxiety associated with mortality (Valentine 2006; McInerney 2007) and are supported by dominant social and biomedical understandings of death as something to be avoided, resisted or at the very least postponed (Bauman 1992). Thus, consistent with the findings of other researchers (Froggatt 2000a; Froggatt 2000b; Ersek et al. 2000; Whittaker et al. 2007), this study illustrates that formal or informal dialogues about death were not part of the culture of care. The collusion of staff members’ in avoiding dialogues about death arguably sustains the rehabilitative/restorative focus of aged care and in turn de-emphasises the complex and often resource-intensive needs of people who have progressive and debilitating life-limiting conditions (such as dementia) (Abbey 1994; Abbey et al. 2006; O’Connor 2009).

The findings of this study suggest that aged care staff, through their unwitting exercise of power, support hegemonic institutional interests that work to trivialise the complex needs of people with dementia in RAC settings, and indeed it could be argued, older people in these settings per se. These circumstances arguably limit the possibilities for aged care staff to practice in ways that support a palliative approach to care, given that this approach is a “needs-based” philosophy of care (ADoHA 2006). Hence, the findings of this study indicate a need to explore strategies that will support aged care staff to develop their care practices to support a palliative approach.

The participation of group members in the reconnaissance reflects what Friere (1970, p.90) might call “conscientization” or the raising of critical consciousness. Through telling their stories and having opportunities to revisit them, the ARG members progressively took up a more-critical agenda in their discussions. Their emerging analyses of how competing cultural, social and material interests impacted on the provision of palliative care on the SCU heightened the group’s awareness that changing practice would be a complex process. As such, they agreed to develop a more comprehensive understanding of some of the issues that had emerged through the reconnaissance. Hence, they progressed to their first action cycle.
Chapter 6: Action Cycle 1 - Scoping the Issues

During the reconnaissance, the ARG members could be understood as having constituted what Kemmis (2001, p.103) referred to as a “communicative space”. As they shared stories about their practice and began to critically engage with issues that were emerging, group members articulated a number of problems that they identified as requiring further investigation. Kemmis and McTaggart (2005, p.346) argued that to gain a “realistic” perceptive about a practice situation(s), prior to planning strategic action, other stakeholder viewpoints in addition to those of participants should be collected. Consistent with this perspective, the group sought to develop a “clear picture of the situation as currently understood and experienced” (Street 1995, p.67) by others in the field. Therefore, Action Cycle 1 consisted of four sub-cycles through which quantitative and qualitative data were first collected from a range of different sources and then analysed (see Figure 2).

Each sub-cycle involved the planning and implementation of an action plan that explored an area of concern arising from the reconnaissance. Sub-cycle one investigated staff knowledge about dementia and a palliative approach; sub-cycle two explored the degree to which resident documentation reflected a palliative approach to care; sub-cycle three elicited family caregivers understandings about dementia, palliation and their experiences in the SCU and sub-cycle four examined how other staff conceptualised and operationalised palliative care in the SCU. As previously discussed in Chapter 4, these sub-cycles were largely facilitated by me. While group members were consulted during this process, I was primarily responsible for the development of the tools, the collection of data and first level analysis of the raw data.

Consistent with the collaborative and reciprocal imperatives of critical action research, the ARG continued to meet during Action Cycle 1 and I returned the findings from each action plan (subsequent to a first level analysis) to them at various points during this time. Quantitative data was presented in table formats with descriptive statistics and qualitative data presented under thematic headings with narratives excerpts provided. By progressively returning data to the ARG members, I facilitated their engagement in an iterative process of making sense of the findings. To ensure that the ARG members had an opportunity to critically reflect on the data as a whole, I also presented an overview (in the form of a Microsoft PowerPoint
presentation) of the key issues following the completion of all data collection and my first level analysis activities. I recounted in my journal that the presentation provided the group with an opportunity to: *consider the “big picture” of how issues meshed together to provide an account of the happening in their practice environment* (Researcher Journal 19 December 2006). Action Cycle 1 occurred across 7 months\(^3\) from July 2006 to January 2007.

As the ARG members critically reflected on the data they had opportunities to, as Street (1995, p.109) explains, “unpick their assumptions and habitual ways of acting”. Following each of their meetings, case notes were developed that provided an account of the group’s discussions. The notes were returned to the group, via email, prior to each successive meeting. This process enabled the group to reflect on their discussions across time and facilitated the development of the second level collaborative analysis of the issues (see Figure 2). This chapter presents each action plan and reports on the findings that were subject to a first level analysis, followed by the ARG’s collaborative analysis of the data. As the group explored the competing interests that shaped how staff in the SCU constructed their practices in relation to a palliative approach, they identified key areas for subsequent action.

\(^3\) 1 month break over Christmas period.
6.1 Sub-cycle 1: staff surveys

The reconnaissance findings revealed that while ARG members held some knowledge of contemporary palliative care principles, there was a dissonance between how palliative care was conceptualised and operationalised in practice in the SCU. Moreover, ARG members had limited insights into their colleagues’ knowledge of palliative care and also held suspicions about staff members’ knowledge in relation to dementia, suggesting that further education may be required. The group members agreed that it was important to rigorously determine the knowledge of SCU staff about palliative care and dementia, before undertaking further planning actions around these perceived issues. The first action plan (Figure 3) was therefore concerned with exploring staff knowledge.
Concern: Staff knowledge of a palliative approach and dementia unknown to the ARG.

Action Plan 1:
Administer questionnaires to SCU staff to evaluate their knowledge about key aspects of a palliative approach and dementia.

Monitoring:
Record research group meetings to develop case notes
Researcher to keep fieldwork journal

Data Sources:
ARG meeting case notes
Survey results
Researcher’s fieldwork journal

Analysis:
First-level analysis by researcher, followed by second-level collaborative analysis with research group.

6.1.1 Plan

As described in Chapter 4, a significant component of planning this action involved the development of two questionnaires, these being: (i) the PAQ and (ii) the KDQ. The ARG members identified that the most effective way to administer the questionnaires was at shift hand-over, as this was the point at which the largest cohort of staff could be captured and was one of the quieter times on the unit. In preparation for the action, the group members alerted their colleagues about the dates for questionnaire administration and planned for a newsletter (see Appendix 11) to be posted on the unit to inform staff of the questionnaire results. I was responsible for data collection, first-level data analysis, and reporting.
6.1.2  Take action and collect data

The PAQ and KDQ were administered and demographic information was collected from all staff members in the SCU. Administration occurred across a 2-week period and respondents were given the option to return their completed survey directly to me in a sealed envelope or return it to a pigeonhole at a different location on the campus at a later time.

6.1.3  First level analysis: researcher facilitated

The first-level analysis of the data is reported below.

6.1.3.1 Respondents

The questionnaires were administered to the 42 staff that worked regularly in the SCU. Of these staff the majority worked either permanent full-time or permanent part-time. Three staff members were casual employees. These staff members indicated that they worked a minimum of approximately 16 hours per fortnight and had been in their current positions for one to six years, hence they were included in the sample. The response rate to the questionnaires was 88% (n=37) and thus representative of the staff on the SCU. Five staff members that did not return the questionnaires comprised three PCAs, one catering staff member and one allied health assistant.

As discussed in Chapter 4, data from different respondents were analysed according to occupational groupings of staff members, these being ‘nursing staff’, ‘direct care staff’ and ‘service staff’. The constituents of each group are represented in Table 6. Labelling the occupational group this way was consistent with terms used at the facility. Therefore, members of the research group were able to easily make sense of the categories. The groupings also helped to maintain the anonymity of respondents and enabled the knowledge levels of those staff with similar educational backgrounds to be analysed.
Table 6  Questionnaire respondents (n=37)

<table>
<thead>
<tr>
<th>Occupational Grouping</th>
<th>Staff Qualification</th>
<th>n (37)</th>
<th>% (100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing staff (n=8)</td>
<td>Registered Nurse (RN)</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Enrolled Nurse (EN)</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Direct Care Staff (n=23)</td>
<td>Personal care assistant (PCA)</td>
<td>20</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td>Allied health assistants</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Service Staff (n=6)</td>
<td>Cleaning staff</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Catering staff</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>37</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

6.1.3.2 Age of respondents

Although the age of respondents varied in each occupational group, the majority of nursing staff (63%), direct care staff (61%) and service staff (67%) were aged 46 years and over. Almost one-quarter of the respondents were aged between 36 and 45 years (nursing staff – 25%; direct care staff – 26%; service staff – 17%). The remaining 14% of respondents were under 35 years old.

6.1.3.3 Qualifications of respondents

Of the nursing staff (n=8), all four RNs and three of the four ENs were hospital-trained. One EN had completed a Level IV TAFE Certificate. Two nursing staff respondents had completed a frontline management course.

Of the direct care staff (n=23), 22% had completed Certificate Level III in aged care, 52% had completed a Certificate Level IV in aged care. One direct care staff respondent had qualifications in an allied health field and two had qualifications unrelated to their caring role. Amongst the service staff (n=6) only one respondent indicated having a related qualification.

6.1.3.4 Work history of respondents

Of the respondents, 32% had been in their current position in the organisation between 1-5 years, and almost 48% indicated being in their position for between 6-10 years and 19% between 11-15 years. Overall, 42% of respondents had worked in the aged care sector for 11 years or more, with 29% of this group being in the sector for more than 15 years. 38% had been in the industry for between 6 and 10 years and
just under 20% for 5 years or less. Overall the respondent demographic data indicates that there was an older cohort of staff on the unit, most of whom had extensive experience of working within the aged care sector.

6.1.3.5 Previous education – palliative care and dementia

Considering that both the PAQ and KDQ tested staff members’ knowledge in relation to a palliative approach and dementia, the education that staff previously had in relation to these areas of practice was also of interest. Therefore, respondents were asked to indicate whether they had learned about palliative care or dementia in the past and the means by which they had acquired their knowledge (e.g. formal or informal). Tables 7 and 8 summarise staff responses about previous palliative care education. Percentages in the following tables that do not sum to 100 indicate missing data.

<table>
<thead>
<tr>
<th>Occupational Groups</th>
<th>Yes (%)</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing staff (n=8)</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Direct care staff (n=23)</td>
<td>74</td>
<td>26</td>
</tr>
<tr>
<td>Service Staff (n=6)</td>
<td>33</td>
<td>67</td>
</tr>
</tbody>
</table>

Nursing and direct care staff had considerably more access to formal education about palliative care than service staff and Table eight provides a summary of the types of education that respondents had attended. To this item, 5 direct care staff and 4 services staff did not respond. Of those that did respond, only one staff member in the sample of respondents, a RN, indicated attendance at a workshop about the national roll-out of the Guidelines (ADoHA 2006). Other formal education attended included in-service or education series conducted by specialist palliative care services, while informal education referred to providing palliative care for a relative.

<table>
<thead>
<tr>
<th>Occupational Groups</th>
<th>Type of education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Formal (%)</td>
</tr>
<tr>
<td>Nursing staff (n=8)</td>
<td>86</td>
</tr>
<tr>
<td>Direct Care Staff (n=17)</td>
<td>71</td>
</tr>
<tr>
<td>Service Staff (n=2)</td>
<td>0</td>
</tr>
</tbody>
</table>
When respondents were asked if they had previously learned about dementia, either through formal education or informally, 68% indicated that they had accessed education of some sort (see Table 9). One direct care staff member did not respond to this item.

Table 9  Previous education about dementia

<table>
<thead>
<tr>
<th>Occupational Group</th>
<th>Yes %</th>
<th>No %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing staff (n=8)</td>
<td>88</td>
<td>12</td>
</tr>
<tr>
<td>Direct care staff (n=22)</td>
<td>73</td>
<td>26</td>
</tr>
<tr>
<td>Service Staff (n=6)</td>
<td>17</td>
<td>83</td>
</tr>
</tbody>
</table>

Table 10 represents the type of dementia education respondents had attended. Five direct care staff and 4 service staff members did not respond to this item. For those that did respond and indicated having attended formal education, this comprised of either in-service sessions held at the facility or an education series conducted by Alzheimer’s Australia. Two respondents also indicated having learned informally about dementia by providing care for a relative with the condition.

Table 10  Type of dementia education attended (formal and informal)

<table>
<thead>
<tr>
<th>Occupational Groups</th>
<th>Type of education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Formal (%)</td>
</tr>
<tr>
<td>Nursing staff (n=8)</td>
<td>100</td>
</tr>
<tr>
<td>Direct Care Staff (n=17)</td>
<td>100</td>
</tr>
<tr>
<td>Service Staff (n=2)</td>
<td>0</td>
</tr>
</tbody>
</table>

Respondents were also asked to specify how long ago they had learned about palliative care and dementia, either by attending education seminars or by other more informal means. However, response rates for these two items were poor, with 60% of the data for the palliative care question and 40% of data for the dementia question missing. As such, the results were not included in the analysis. Nonetheless, the findings indicate that the majority of nursing and direct care staff from the SCU had at some stage accessed formal education in relation to palliative care and dementia, accounting for some background knowledge. However, service staff from the unit
had not previously undertaken any formal education, but may have developed some knowledge through informal processes.

The three casual staff members who were surveyed indicated that they had never attended any formal education sessions or learnt informally about palliative care or dementia in the past.

6.1.3.6 Palliative Approach Questionnaire (PAQ)

The PAQ contained 21 items and tested respondents’ knowledge of a palliative approach. The response options were on a 5 point Likert-type scale, ranging from ‘strongly agree’ (1) to ‘strongly disagree’ (5), with ‘not sure’ (3) as an option. For the purposes of analysis reverse scored questions were recoded and ‘strongly agree’ and ‘agree’ responses were collapsed together as correct; ‘strongly disagree’ and ‘disagree’ were treated as incorrect and ‘not sure’ responses were separated out. The Cronbach’s Alpha Co-efficient was calculated as a measure of the internal consistency reliability (George & Mallery 2003) of the tool. The Alpha Co-efficient was 0.68.

Descriptive statistics were used to examine the number of questions answered correctly by respondents in each occupational group. In Figure 5 the frequencies of correct responses for each occupational group are provided, and show that:

- 7 of the 8 nursing staff correctly answered 80% or more of the items on the PAQ;
- 21 of 23 direct care staff correctly answered 80% or more of the items on the PAQ; and
- 3 of the 6 service staff correctly answered 80% or more of the items on the PAQ.

These results indicate that, overall, respondents demonstrated a good basic understanding of the principles of a palliative approach. Service staff were more variable in their performance compared to the other groups with the numbers of questions answered correctly ranging from 12 to 19 out of 21. The small sample size of this group makes it difficult to draw further conclusions. Based on the findings an intervention requiring a post-test administration of the PAQ appeared not to be warranted.
Examining the breakdown of responses to individual items within the PAQ provides further insights into the knowledge base of staff members. Differences in knowledge among the occupational groups were evident on a number of selected questions. These differences are discussed below.

**Item Six** on the PAQ, which stated, ‘A palliative approach needs a referral from a doctor before it can be implemented’, was correctly answered if the respondent endorsed ‘strongly disagree’ or ‘disagree’. As demonstrated in Table 11, direct care staff had a greater understanding than both nursing staff and service staff with respect to this item.

### Table 11 Responses to item 6 on the PAQ

<table>
<thead>
<tr>
<th></th>
<th>Nursing staff (n=8)</th>
<th>Direct Care Staff (n=23)</th>
<th>Service Staff (n=6)</th>
<th>Total (n=37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree</td>
<td>3 (37.5%)</td>
<td>3 (13%)</td>
<td>2 (33.3%)</td>
<td>8 (21.6%)</td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (12.5%)</td>
<td>10 (43.5%)</td>
<td>3 (50%)</td>
<td>14 (37.8%)</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>3 (37.5%)</td>
<td>10 (43.5%)</td>
<td>0 (0%)</td>
<td>13 (35.1%)</td>
</tr>
<tr>
<td>Not Sure</td>
<td>1 (12.5%)</td>
<td>0 (0%)</td>
<td>1 (16.7%)</td>
<td>2 (5.4%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8</td>
<td>23</td>
<td>6</td>
<td>37 (100%)</td>
</tr>
</tbody>
</table>

**Item Nine** on the PAQ, which stated, ‘A palliative approach is another name for terminal or end-of-life care?’ was correctly answered by the respondent endorsing ‘strongly disagree’ or ‘disagree’. As indicated in Table 12, the majority of respondents incorrectly answered this statement. Data that indicated how long ago
nursing and direct care staff had undertaken formal education about palliative care
would have helped explain these results, as advances in the last five to ten years has
seen the definition of palliation shift away from only including end-of-life care.

Table 12  Responses to item 9 on the PAQ

<table>
<thead>
<tr>
<th></th>
<th>Nursing staff (n=8)</th>
<th>Direct Care Staff (n=23)</th>
<th>Service Staff (n=6)</th>
<th>Total (n=37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>2 (25%)</td>
<td>4 (17.4%)</td>
<td>1 (16.7%)</td>
<td>7 (18.9%)</td>
</tr>
<tr>
<td>Agree</td>
<td>3 (37.5%)</td>
<td>9 (39.1%)</td>
<td>5 (83.3%)</td>
<td>17 (45.9%)</td>
</tr>
<tr>
<td>Disagree</td>
<td>3 (37.5%)</td>
<td>8 (34.8%)</td>
<td>0 (0%)</td>
<td>11 (29.7%)</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>0 (0%)</td>
<td>1 (4.3%)</td>
<td>0 (0%)</td>
<td>1 (2.7%)</td>
</tr>
<tr>
<td>Not Sure</td>
<td>0 (0%)</td>
<td>1 (4.3%)</td>
<td>0 (0%)</td>
<td>1 (2.7%)</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>23</td>
<td>6</td>
<td>37 (100%)</td>
</tr>
</tbody>
</table>

**Item Ten** on the PAQ, which stated, ‘A palliative approach can be suitable for people with dementia’, was correctly answered by the respondent either ‘strongly agree’ or ‘agree’ with the statement. Table 13 indicates that most staff considered a palliative approach was appropriate for people with dementia.

Table 13  Responses to item 10 on the PAQ

<table>
<thead>
<tr>
<th></th>
<th>Nursing staff (n=8)</th>
<th>Direct Care Staff (n=23)</th>
<th>Service Staff (n=6)</th>
<th>Total (n=37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>5 (62.5%)</td>
<td>5 (21.7%)</td>
<td>2 (33.3%)</td>
<td>12 (32.4%)</td>
</tr>
<tr>
<td>Agree</td>
<td>1 (12.5%)</td>
<td>18 (78.3%)</td>
<td>4 (66.7%)</td>
<td>23 (62.2%)</td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (12.5%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1 (2.7%)</td>
</tr>
<tr>
<td>Not Sure</td>
<td>1 (12.5%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1 (2.7%)</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>23</td>
<td>6</td>
<td>37 (100%)</td>
</tr>
</tbody>
</table>

**Item Thirteen** on the PAQ which stated, ‘A palliative approach needs to be delivered by staff with qualifications in palliative care’ was correctly answered by the respondent endorsing ‘strongly disagree’ or ‘disagree’. The results are represented in Table 14.
Table 14  Responses to item 13 on the PAQ

<table>
<thead>
<tr>
<th></th>
<th>Nursing staff (n=8)</th>
<th>Direct Care Staff (n=22)</th>
<th>Service Staff (n=6)</th>
<th>Total (n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>0 (0%)</td>
<td>3 (13.6%)</td>
<td>0 (0%)</td>
<td>3 (8.3%)</td>
</tr>
<tr>
<td>Agree</td>
<td>0 (0%)</td>
<td>5 (22.7%)</td>
<td>6 (100.0%)</td>
<td>11 (30.6%)</td>
</tr>
<tr>
<td>Disagree</td>
<td>5 (62.5%)</td>
<td>13 (59.1%)</td>
<td>0 (0%)</td>
<td>18 (50%)</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>2 (25%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>2 (5.6%)</td>
</tr>
<tr>
<td>Not Sure</td>
<td>1 (12.5%)</td>
<td>1 (4.5%)</td>
<td>0 (0%)</td>
<td>5 (5.6%)</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>22</td>
<td>6</td>
<td>36 (100%)</td>
</tr>
</tbody>
</table>

6.1.3.7 Knowledge of Dementia Quiz

The KDQ contained 22 items measuring staff members’ knowledge of dementia across two sub-scales; (i) treatment and care, and (ii) signs and symptoms. The tool had three response options (‘true’, ‘false’ and ‘unsure’). However, during analysis the items were treated as dichotomous (true = correct, and false/unsure = incorrect). The Kuder- Richardson co-efficient (KR21) was used calculate the reliability of the KDQ. This test is used when variables are dichotomously scored and provides a measure of internal consistency reliability (George & Mallery 2003). The KR21 was 0.62. Subscales also indicated poor internal consistency reliability. The treatment and care subscale (13 items) had a KR21 of 0.51, while the signs and symptoms subscale (9 items) had a KR21 of 0.07.

Descriptive statistics were calculated from KDQ responses, with reference to the three occupational groups. Figure 6 shows the percentage of total correct answers for each occupational group. Nursing staff and direct care staff demonstrated a good basic understanding of dementia. One direct-care staff member, who was an ECA, demonstrated an excellent knowledge base – answering all 22 questions correctly. Although service staff did not perform as well as the other groups, one member demonstrated a good level of knowledge, answering 19 out of the 22 items correctly. This particular staff member had been working in the SCU for nine years.
Analyses were conducted on the two subscales contained within the questionnaire to examine the correct responses for each occupational group. These results are presented in Figures 7 and 8.

**Figure 7**  Percentage of total correct responses, treatment and care subscale
In summary, the results reveal that there was not a great deal of difference between how nursing staff responded to the KDQ compared to the direct care staff. Both groups demonstrated a very good basic understanding of dementia and related care practices, thus supporting earlier data which indicated that the majority of these staff had undertaken some form of peer delivered education. Service staff did not perform as well, consistent with demographic data that indicated that none of them had been involved in any type of formal education about dementia.

As with the PAQ, the breakdown of responses to individual items on the KDQ provides further useful insights into staff knowledge of dementia. Even though 22 of the 23 KDQ questions were answered correctly by more than 50% of staff, nuances were evident in the responses of the different occupational groups to some items. These nuances are discussed below.

**Item One** on the KDQ, “Memory loss is a normal part of the ageing process” was correctly answered by the respondent indicating a ‘false’ response. As demonstrated in Table 15, the majority of respondents incorrectly answered the above statement.
Table 15  Responses item 1 of KDQ

<table>
<thead>
<tr>
<th></th>
<th>Nursing staff (n=7)</th>
<th>Direct Care Staff (n=23)</th>
<th>Service Staff (n=6)</th>
<th>Total (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>True</td>
<td>6 (75%)</td>
<td>11 (52.4%)</td>
<td>4 (66.7%)</td>
<td>21 (60%)</td>
</tr>
<tr>
<td>False</td>
<td>2 (25%)</td>
<td>9 (42.9%)</td>
<td>1 (16.7%)</td>
<td>12 (34.3%)</td>
</tr>
<tr>
<td>Unsure</td>
<td>0 (0%)</td>
<td>1 (4.8%)</td>
<td>1 (16.7%)</td>
<td>2 (5.7%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8 (100%)</td>
<td>21 (100%)</td>
<td>6 (100%)</td>
<td>35 (100%)</td>
</tr>
</tbody>
</table>

**Item 9** on the KDQ, ‘People with dementia depend more on what is said than upon non-verbal cues (e.g. body language, signs)’, was correctly answered by respondents choosing a ‘false’ response. The results are demonstrated in Table 16.

Table 16  Responses item 9 of KDQ

<table>
<thead>
<tr>
<th></th>
<th>Nursing staff (n=7)</th>
<th>Direct Care Staff (n=23)</th>
<th>Service Staff (n=6)</th>
<th>Total (n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>True</td>
<td>1 (14.3%)</td>
<td>7 (30.4%)</td>
<td>3 (50%)</td>
<td>11 (30.6%)</td>
</tr>
<tr>
<td>False</td>
<td>6 (85.7%)</td>
<td>13 (56.5%)</td>
<td>3 (50%)</td>
<td>22 (61.1%)</td>
</tr>
<tr>
<td>Unsure</td>
<td>0 (0%)</td>
<td>3 (13%)</td>
<td>0 (0%)</td>
<td>3 (8.3%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>7 (100%)</td>
<td>23 (100%)</td>
<td>6 (100%)</td>
<td>36 (100%)</td>
</tr>
</tbody>
</table>

6.1.4  Reflection of ARG members: collaborative analysis of the data

Findings from the questionnaires were presented to the ARG members in a similar format to the data presented above. It was apparent from their early discussions that the group’s interest lay primarily in exploring findings from the PAQ. A key concern that emerged was related to the traditional understandings held by the majority of SCU staff about who could implement a palliative approach and when it should be implemented. These issues led ARG members to reflect on their previous educational encounters around palliative care. Their discussions revealed the absence of a formal educational program at the facility that focused on contemporary palliative care. The reflections of the ARG members highlighted the organisation’s reliance on external agencies, such as specialist palliative care services, to provide education. This situation meant that staff in the SCU accessed education in an
intermittent manner, as there were usually limited places available for those who wished to attend. For example, Judy stated that she hadn’t attended an education session on palliative care for ‘a long time’. Likewise, Elizabeth and Catherine recalled having been to a series of education sessions conducted a number of years ago, but were unable to recall exactly when this was. Heather explained that for the most recent education delivered by specialist services ‘there was [sic] only four places’ available for staff from the facility to attend, despite a much larger number of staff registering their interest. Reflecting on the episodic access of staff members to palliative care education the ARG members emphasised that attendance at education sessions was not mandated as compulsory for all staff, unlike some other education (fires safety, CPR training).

While ARG members indicated that they valued the opportunity to attend external education sessions, they raised concerns that the information presented was often not tailored to the needs of aged care staff. For example, Heather despondently stated:

...there is usually nothing specific [to aged care]. The last education session I went to on palliative care was such a bloody waste of time, 8 hours and they had [a Dr] from the oncology unit talking for an hour and a half on chemotherapy...we probably shouldn’t have been there.

During the ARG’s discussions none of the members mentioned the conduct of the educational workshops around the Guidelines (ADoHA, 2006) that had been conducted nationally across the aged care sector. Indeed, this was not surprising given that during the reconnaissance discussions Heather was found to be the only group member who was aware that the Guidelines (ADoHA, 2006) existed (see p.118). When I questioned the group about their knowledge of the national workshops, again Heather was the only group member who knew about their conduct. She explained that she and another nurse⁴ from the facility had actually attended the education and had been provided with a resource kit that was meant to assist with championing the implementation of the Guidelines (ADoHA, 2006) at their facility. However, Heather argued that it was ‘almost impossible’ to take on such extra responsibilities with her current workloads. Heather claimed there was little managerial support and a shortage of resources and explained that conditions on the unit were not conducive to changing practice:

⁴ This staff member did not return a questionnaire.
...you come back to work [after the workshop] and your short staffed and there’s not a lot of support from management cause they are concerned with other things and it’s [education] just not given priority because there are other issues which need to be dealt with straight away...I’ve still got the box [resource kit] sitting at home...

As the group members critically reflected on their limited knowledge of the palliative care guidelines (ADoHA, 2006), they revealed their own passivity in locating evidence or any other information that would inform their practices. It became apparent that they relied on the Assistant Director of Nursing (ADON) to distribute such information. Hence, Anne stated that information, ‘usually comes from [the ADON]... that’s how we find out’. Catherine explained that the information ‘went through the [nurse] supervisor’ who then passed it on to staff. As ARG members reflected on their reliance on others, they recognised a need to improve information sharing and access to appropriate education about a palliative approach and the Guidelines (ADoHA, 2006). However, as Judy considered the implications of staff having greater access to education and evidence-based resources, she suggested that it was not the role of SCU staff to actually initiate a palliative approach. She stated: ‘I think the decision should be the GPs, they are the one’s responsible...because they need to review [the resident]’. Indeed, this comment was in keeping with the findings of the PAQ that indicated four out of the eight nursing staff surveyed believed a palliative approach needed a referral from a GP to be initiated. However, Heather contested this view and argued that the implementation of a palliative approach was not dependent on the GP. Heather explained that SCU staff could ‘make many decisions’ about the care of residents that improved their comfort and dignity, that did not require approval from a GP. Reflecting on Heather’s comments, led Anne to assert that facility staff ‘knew the resident best’ which meant that they were in an ideal position to ‘pick up on changes [deterioration]’ and ‘take the lead’ to provide a palliative approach. In response to this lively discussion Judy conceded that SCU staff and in particular nursing staff, had a ‘responsibility’ to be more proactive.

From the group’s critical reflections emerged changes in their understandings. The group members shared a new recognition of their responsibility in improving their own and other staff members’ knowledge of a palliative approach. This change was evident when Anne asserted ‘we need to do in-service education’ arguing that it
would ensure staff ‘have a better understanding of [a] palliative approach’. Judy believed that education would assist staff to understand that palliative care could be implemented, as she stated ‘in the early days’ of the resident’s stay on the SCU. Moreover, Catherine highlighted that the education would not only result in ‘improved understanding’ but she suggested that it may also ‘improve communication’ between staff by offering opportunities ‘to talk’ about issues associated with death and dying. Based on these new understandings the ARG members devised a focus for action: to provide education sessions for SCU staff with the aim of improving their understandings of a palliative approach and increasing their awareness of the Guidelines (ADoHA 2006). A more detailed account of the group’s planning activities is presented in Chapter 8.

6.2 Sub-cycle 2: resident documentation audit

In addition to the ARG’s concerns during the reconnaissance discussions about the knowledge of SCU staff with respect to a palliative approach and dementia, they also questioned the effectiveness of resident documentation in directing care practices. Given that the group members had revealed a number of contradictions in how palliative care was conceptualised and operationalised, they were keen to explore the extent to which resident documentation reflected a palliative approach. Therefore, group members planned to undertake an audit of resident documentation.

**Figure 9  Action Plan 2**

**Concern:** Issues raised about the effectiveness of resident documentation in directing resident care practice and the extent to which documentation reflects a palliative approach to care.

**Action Plan 2:**
Audit resident documentation

**Monitoring:**
Record research group meetings to develop case notes
Researcher to keep fieldwork journal

**Data Sources:**
Research meeting case notes
Audit results
Researcher’s fieldwork journal

**Analysis:**
Researcher responsible for first level analysis, followed by second level collaborative analysis with research group.
6.2.1 Plan

Figure 10  Action Plan 2 – Documentation audit

Planning this action involved the development of an audit tool and the identification of documentation sources to audit, as discussed in Chapter 4. The audit tool contained eight domains and corresponding audit criteria (see Appendix 8).

6.2.2 Take action and collect data

A total of 21 resident files were audited. Of these, 15 files of current residents (40% of the SCU resident population) were audited across domains 1 to 5 and the 6 files of residents who had died on the SCU in the previous 6 months were audited across domains 6 to 8. Data sources that were audited included

- Resident Health and Life Assessment [HLA];
- RCS documentation;
- care plan; and
- resident care daily notes and medical notes.

See Chapter 4, p.92 for information related to audit method.

6.2.3 First level analysis: researcher facilitated

The first level analysis of the audit results are reported here. Findings for the 15 resident files audited across domains 1 to 5 are presented first followed by the findings from the 6 deceased resident files audited across domains 6 to 8.

6.2.3.4 Audit domains 1 to 5

Table 17 below summarises the number of resident files that met the audit criteria and the documentation source (e.g. care plan; HLA; and daily care notes including
RCS) in which the information was located. Medical notes have not been included as only one resident’s medical documentation met an audit criteria.

With a broad range of resident documentation being audited some documentation sources were not expected to contain information related to certain audit criteria. Staff documentation at the facility is required to follow specific processes (see Appendix 12) and therefore certain information which is relevant to one source of documentation may not be relevant to others. For example, as demonstrated in Table 17, for audit criterion 1.1, an advance care plan document would be expected to be present in either the resident HLA or the care plan. It would not be expected to be located in daily care notes and therefore ‘not applicable’ (N/A) has been used to denote this.

5 A doctor recommended that a resident be referred to a physiotherapist to assist with falls management.
Table 17: Result of resident documentation audit for domains 1 to 5 (n=15)

<table>
<thead>
<tr>
<th>Audit Domain</th>
<th>Audit Criteria</th>
<th>Number of resident files that met audit criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Resident HLA</td>
</tr>
<tr>
<td>1. Advance care planning</td>
<td>1.1 Presence of an advance care planning document</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>1.2 Presence of ‘enduring guardian’ documentation</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>1.3 Indication of ‘person responsible’ for decision making</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>1.4 Documented wishes of the person responsible in relation to resident deterioration</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>1.5 Documented wishes of the person responsible in relation to transfer to an acute setting, in event of health deterioration.</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>1.6 Documentation indicating meetings between family, health care team and where appropriate the resident re: advance care planning</td>
<td>0</td>
</tr>
<tr>
<td>2. Symptom Assessment &amp; Management</td>
<td>2.1 Evidence of comprehensive assessment on admission</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>2.2 Evidence of review of comprehensive symptom assessment within the last 12 months or earlier if indicated.</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>2.3 Evidence of regular review of symptom management techniques (in relation to comprehensive assessment)</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>2.4 Evidence of assessment and management processes for symptoms</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>2.5 Documented non-pharmacological interventions for symptom management</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>2.6 Documented of multidisciplinary input to assist symptom management.</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>2.7 Nutritional Management: Food choices documented</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Size of meal documented</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2.8 Future wishes of resident or family documented about nutrition and hydration in event of deterioration in the resident’s condition.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2.9 Skin integrity: Assessment Interventions for pressure area care documented.</td>
<td>11</td>
</tr>
<tr>
<td>3. Psychological Support</td>
<td>3.1 Use of screening tools (i.e. depression assessment, delirium assessment)</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>3.2 Evidence of input/consultation from specialists services (input if necessary according to residents needs) –</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>➢ psycho geriatric</td>
<td></td>
</tr>
<tr>
<td></td>
<td>➢ Dementia support unit</td>
<td></td>
</tr>
<tr>
<td></td>
<td>➢ Specialist Palliative Care</td>
<td></td>
</tr>
<tr>
<td>4. Family Support</td>
<td>4.1 Documented discussions with family regarding the resident’s condition.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>4.2 Documented discussions with family relating to the course of the illness/possible trajectory.</td>
<td>0</td>
</tr>
<tr>
<td>4. Family Support</td>
<td>4.3 Documented discussions relating to future care/treatment options and level of involvement family wishes to have.</td>
<td>0</td>
</tr>
<tr>
<td>4. Family Support</td>
<td>4.4 Documented discussions with family related to cultural concerns.</td>
<td>1</td>
</tr>
</tbody>
</table>
The volume of data collected by the audit was large and discussion of all results is not practicable, therefore, a summary of key findings is provided. Numbered references that refer to audit criteria in Table 17 (e.g. [1.1], [1.2]) are included in the summaries for ease of reference.

**Domain 1: Advance care planning**

Key findings:

- No advance care plan documents were located [1.1].
- No residents had a legally appointed guardian\(^6\) responsible for medical/health decisions [1.2].
- All residents had a documented ‘person responsible’\(^7\) for decision-making [1.3].
- Limited individualised documentation relating to future care wishes/treatment decisions. [1.4, 1.5].

  - For example, the palliative care planning sections of the HLA (see Appendix 14) in seven residents’ files contained almost identical entries relating to hospital transfer. These stated that the resident was to ‘remain within the facility for a slowly deteriorating condition or transfer to hospital if acute care is needed’. No additional information was present. Nine resident care plans stated that the resident was to ‘remain within the facility for a slowly deteriorating condition or transfer to hospital if acute care is needed’.

---

\(^6\) In Tasmania this person is referred to as ‘Enduring Guardian’ (*Guardianship and Administration Act 1995*(Tas)). In other states of Australia this person may also be known as an ‘Enduring Power of Attorney’ for personal/health matters (Cartwright & Parker 2004, p. 816)

\(^7\) A ‘person responsible’ is a person who is able to give substitute consent to medical treatment and other health related decisions for an adult when they are no longer capable of giving their own consent, pursuant to the section 4(5) of the *Guardianship and Administration Act 1995* (Tas).
• No evidence of meetings among health care team, family and where appropriate, the resident, to discuss issues of ACP [1.6].

• Inconsistencies between information documented in palliative care planning sections of the resident HLA and the corresponding care plan occurred in six resident files.

Domain2: Symptom assessments and management

Key Findings:

• Comprehensive assessment of symptoms around the time of admission was contained within the HLA. 14 of the 15 resident notes audited had assessments completed on admission [2.1].

• Symptom assessments in the HLA had undergone a regular process of review, indicated by staff members signing and dating the assessments for each review period (4 monthly or earlier if indicated) [2.2].

• Symptom management techniques in the HLA and residents’ care plan were documented as having been reviewed on a 4 monthly basis or earlier if indicated [2.3].

• All residents had a range of non-pharmacological symptom management strategies documented in the HLA and care plans. These included the use of hot packs, massage, exercise and aromatherapy [2.5]. Within the daily care notes and RCS documentation, non-pharmacological strategies to assist symptom management were primarily documented by diversional therapy staff and related to assisting residents with passive exercises. There was little other individualised documentation present in care notes [2.5]. Multi-disciplinary input to assist symptom management (mostly related to pain and behaviour management) was documented in all resident HLAs. These entries related mostly to diversional therapy and physiotherapy assessments, with interventions documented in the resident care plans [2.6]. Three referrals to other consultancy services were also located, one to a dementia support unit and two to specialist palliative care services. Within resident care notes and RCS documentation the majority of entries related to multi-disciplinary input were made by diversional therapy staff, which related the involvement of resident in ‘lifestyle and leisure activities’ [2.6].

• No documentation was evident in relation to future decisions about nutrition and hydration, in the event that the resident’s condition deteriorated [2.8].
• Skin integrity assessments and strategies to reduce the development of pressure areas were documented in the majority of resident notes [2.9].

Assessment and Management of Symptoms [2.4]:
Resident daily care notes contained entries related to the assessment and management of incidental pain [2.4] as per facility guidelines for exception reporting. The two most-commonly cited symptoms across the 12 month retrospective audit period were agitation and pain. Documentation related to assessment and management of these symptoms indicated a number of issues (for detailed results see Appendix 13):

• Limited evidence of formal assessment tools being used to assess pain or agitation.
• The most-common type of intervention documented in residents’ care notes to manage episodes of agitation and pain was pharmacological, despite a range of non-pharmacological strategies being documented in residents’ HLAs and care plans.
• Documentation about the effect/outcome of pharmacological interventions was limited. Entries were non-descriptive and included inadequate information to inform further decision-making.
• Limited evidence of review of symptom management strategies.

Domain 3: Psychological support

Key Findings:
• Fourteen of the 15 residents had a depression assessment documented [3.1].
• Six residents had input/consultation from specialist services (psycho-geriatrician, dementia support unit), to assist with behaviour management [3.2].
• Resident care plans indicated a range of non-pharmacological strategies prescribed to provide psychological support to residents [3.3]. The majority of these interventions were documented as being provided by the diversional therapy staff and largely focused on maintaining residents’ social engagement (e.g. group activities). Three residents were documented as requiring one-on-one support from diversional therapists for anxiety management.

4. Family Support

Key findings:
Limited evidence across all sources of documentation that discussions had occurred with family caregivers/person responsible in relation to the resident’s condition [4.1]. Three entries, located in daily care notes, indicated discussions with family or the ‘person responsible’. These entries contained little detail as to the actual content of the discussion. For example, all three entries stated ‘10 minutes was spent informing family of resident’s health and wellbeing’.

No documentation of discussions about the course or possible trajectory of the dementia evident [4.2].

No documentation of discussions with family/person responsible, about future treatment options for the resident or the family’s/responsible person’s preferred level of involvement in care [4.3].

No formal assessment; in the resident HLA, care plan or daily care notes; of needs of family/person responsible [4.6]. However, within two resident care plans, in the section ‘family needs’, there was documentation to indicate specific needs (e.g. one entry stated: *wife requires much support and reassurance from staff*. ‘Provide information about support networks such as dementia support units and pastoral care’).

Despite the absence of information about family caregiver’s needs, supportive interventions for family caregivers were documented in the resident HLAs and in most of the resident care plans [4.7]. For example:

- In six care plans, interventions directed staff to involve the family in decisions relating to care and care planning.
- Eight care plans directed staff to provide information to the family about support services (e.g. advocacy, pastoral care, family and resident meetings).
- Three care plans stated that staff were to provide information to family caregivers about the progression of dementia.

It is unclear how these interventions were chosen for specific family caregivers or the ‘person responsible’ given the absence of assessment or any documented discussions with staff.

**Domain 5: Spiritual support**

Key Findings:

As part of the routine admission documentation:

- All residents had their spiritual or religious orientation documented [5.1].
• Specific spiritual wishes were noted [5.2].
• All residents had at some stage been seen by the facility pastoral carer [5.3].

Audit findings: domains 6 to 8

The second section of the audit comprising domains 6 to 8 was used to examine the notes of six former residents who had died in the SCU in the previous 6 months. The resident’s files were audited across these domains to capture a snapshot of documentation relating to the dying phase. The results are summarised in Table 18.

Table 18  Result of resident documentation audit for domains 6 to 8 (n=6)

<table>
<thead>
<tr>
<th>Audit Domain</th>
<th>Criteria</th>
<th>Number of notes that met audit criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>HLA</td>
</tr>
<tr>
<td>6. Recognition of the dying phase</td>
<td>6.1 Documented discussion with family re: resident’s deteriorating condition and clarification of care goals.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>6.2 Evidence of discussion re: changes that the family can expect during the terminal phase</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>6.3 Evidence of discussion re: family preferences for visiting (i.e. if family wish to be present at time of death/involved with care)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>6.4 Documentation of signs indicating movement into an end-of-life phase.</td>
<td>N/A</td>
</tr>
<tr>
<td>7. Review of care plan for dying phase</td>
<td>7.1 Medication review – unnecessary medication ceased and PRN medication ordered via alternate routes.</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>7.2 Documented discussion regarding hydration in terminal phase</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>7.3 Documentation in relation to mouth care</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>7.4 Skin care: position changes and pressure relieving devices.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>7.5 Evidence of pain assessment or documentation relating to resident discomfort.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>7.6 Use of end-of-life assessment tool for pain and discomfort.</td>
<td>0</td>
</tr>
<tr>
<td>8. Bereavement Support</td>
<td>8.1 Identification of bereavement support interventions for family caregivers/significant others</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>8.2 Evidence of follow-up bereavement support (i.e. information, referral services, phone call by staff)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>8.3 Card or letter sent to the family following death of the resident</td>
<td>0</td>
</tr>
</tbody>
</table>

Domain 6: Recognition of the dying phase

Key Findings:

• Documentation of communication between family and nursing/medical staff occurred between 2-10 days prior to the resident’s death. Documentation was non-descriptive and provided little detail about the content of discussions [6.1].
For example typical entries by nursing staff included, ‘spent one hour with family informing them of resident’s health status’, ‘care update provided to family’, ‘care update provided of further deterioration’, ‘informed next of kin of doctor’s visit and resident’s health and wellbeing’.

- No documentation indicated whether or not family caregivers were informed about the changes they could expect during the terminal phase of the resident’s condition. [6.2]
- Documentation in relation to family caregivers’ preferences for visiting their relative was absent across all documentation sources, with the exception of one entry in a resident’s daily care notes which indicated that the resident’s family wished to be contacted at any time during the terminal phase. [6.3]
- Documentation was present in daily care notes of three residents relating to the presence of clinical signs indicating that a resident had moved into an end-of-life phase. [6.4]

Domain 7: Review of care plan for dying phase

Key findings:

- No evidence was found that resident care plans were reviewed once the resident had progressed into a terminal phase. Documentation in relation to care was located primarily in daily care notes.
- Medication reviews were documented in all of the resident’s daily care notes during the terminal phase [7.1]. The inability to swallow was documented as a common precursor for medication review.
- There was no documented evidence of discussions with family caregivers about issues related to hydration for the dying person [7.2]. Mouth care procedures were documented in all resident daily care notes. [7.3].
- Considerations in relation to pressure care were infrequently documented [7.4].
- No formal pain or discomfort assessments were located for any of the residents during the terminal phase [7.5, 7.6].

Domain 8: Bereavement support

There was no documentation in any resident’s files relating to bereavement support for family/significant others of the deceased residents [8.1-8.3].
6.2.4 Reflection of ARG members: collaborative analysis of the data

During their initial engagement with the audit data the ARG members critically reflected on the general lack of specificity in their documentation. These discussions revealed the implications of perfunctory documentation practices that staff members had uncritically embraced as part of their ‘everyday’ routines. Judy’s account highlights the technical approach to completing documentation that seemingly disregarded the individuality of resident needs:

\[
\text{to be quite honest... I must admit, you get a [new] resident like Betty, who is similar to another resident like Mary... because I’ve already done Mary’s [HLA documentation], I will use it to give me prompts...}
\]

Reflecting on Judy’s account Anne added ‘I am the same on [my] shift’. The use of an existing resident’s documentation as a template to assist with the completion admission forms for a new resident was highlighted as an essential strategy to negotiate admission documentation in an already hectic day. As Judy explained ‘you are so rushed some days, you don’t have time to sit and think as a whole [about the new resident]’. Through the course of the ARG discussions it became apparent that the dominance of administrative demands on the role of nurses were supported through regulatory structures of the aged care system. For example, Heather explained that representatives of the aged care regulatory authority (the Aged Care Standards and Accreditation Agency), known in the industry as “validators”, had previously praised the volume of resident documentation that staff at the facility produced. Having been present at numerous accreditation visits Heather asserted: ‘...they [validators]...love it!’ Reflective of the hierarchical nature of the aged care environment, the ARG members emphatically agreed that it was important to keep the validators ‘on side’, even at times when this meant complying with what seemed excessive documentation demands. For example, Heather reported that during a previous visit from the accreditation agency, the validators suggested that a new section (related to residents’ sleep patterns) be added to the template for resident care plans. Despite this document already being, as Heather described, ‘forty pages’ in length, she indicated that staff felt powerless to challenge these dominant power relations. She stated:

\[
\text{they [the validators] just come in and say... I think it will be a good idea if you started [a sleep section of the care]... and everybody is just going with it... ‘cause they suggested that it is a good thing!}
\]
The group members were confronted with further evidence of a culture of compliance on the SCU when they reviewed the audit findings that (Domain 1: ACP) indicated there was; (i) no evidence of formal meetings between the health care team and family caregivers for palliative care planning, (ii) no evidence of discussions having occurred with family caregivers about their wishes for the resident’s care at end-of-life, and (iii) little individualised information that could inform direct care processes at points of deterioration in the resident’s condition. When reviewing these data, both Judy and Anne agreed that their palliative care planning documentation was usually repetitive and generic in nature. For example, Judy stated:

_I know I’m guilty of writing [the same thing,] ‘transfer or remain at facility for deteriorating condition, discuss with family and doctor at the time of deterioration’._

While such documentation apparently satisfied the validators, it also suggested that staff did not pursue sensitive topics with family caregivers. Reflecting on the perfunctory nature of their documentation, Anne asserted that the structure of the palliative care planning form (Appendix 14) did not have a person-centred focus. She argued that some of the questions were ‘irrelevant’ and did not encourage nursing staff to elicit detailed information from family caregivers about their wishes related to end-of-life care. Judy agreed with these sentiments and argued that more ‘specific’ planning questions could provide a structured way of approaching sensitive conversations with family. As will become evident later in this chapter, the data from the critical dialogues with RACF staff prompted a further analysis of this issue. However, at this stage, the ARG members identified a second focus for action: to review the palliative care form used at the RACF.

Reflective of their emerging critical awareness about how regulatory and institutional agendas shaped practice, the ARG members were ‘not surprised’ when they reviewed the audit results about symptom assessment and management, which revealed that documentation did not conform to best-practice standards (APS 2005). When reflecting on the data that suggested a limited use of formal pain assessment tools by staff, Judy stated that, with the exception of admission (resident HLA) and annual RCS documentation, nursing staff didn’t usually undertake pain assessments during everyday practice. The group’s reflections suggested that formal pain assessments were done mostly to satisfy institutional and regulatory requirements. Hence, Judy explained that she understood the impetus for conducting formal
assessments was largely related to accruing ‘more (RCS) points’ – that had a direct impact on the organisation’s funding. In support of this contention, the only formal pain assessments located during the audit were included as part of residents’ RCS documentation.

Not surprisingly, nursing staff (RN/EN) in the ARG described subjective processes of decision-making in relation to pain management. They described relying on proxy reports from PCAs to alert them to residents who were displaying symptoms of discomfort. When considering the audit data that indicated a lack of documentation relating to the effect/outcome of interventions for residents, the group members cited the impacts of heavy work demands. For example, Heather explained that staff may not document the effect of providing analgesia to a resident in an attempt to ration the amount of paperwork on their shift. She stated: ‘we have got that much bloody documentation ... staff don’t often... go back and document the effects (of the PRN medication)...because that’s one less documentation you’ve got to do’. Here, Anne, an EN, explained that she would write a brief account, in the notes of residents to whom she had administered analgesia. She stated that at the end of the shift she would write: ‘PRN paracetamol given for discomfort with effect’. Anne argued that she couldn’t afford to do a greater amount of documentation during her shift, without considerable imposition on her time (presumably as documenting a formal assessment would have).

Reflecting on the emerging narrative, Judy suggested an awareness that pain management practices on the SCU were not consistent with best practice standards when she stated: ‘we [nursing staff] should be completing the Abbey (non-verbal pain assessment scale) before we go with any analgesia!’ This was an important comment because it alerted other group members to their seemingly uncritical reliance on subjective, ad hoc decision-making processes. Interestingly, at no point during their discussions did group members refer to the recently-released “Pain in Residential Aged Care Facilities - Management Strategies” (APS 2005). When we discussed the aforementioned best-practice document (APS 2005), they were intrigued to learn of its existence. After having had an opportunity to review the document in the context of a subsequent meeting, there was a discernable shift in the perspectives of group members. Demonstrative of a change in understandings, the ARG recognised an imperative to reconsider their pain management practices.
Hence, they identified a focus for action: to explore strategies to develop evidence based pain assessment and management practices on the SCU.

6.3 Sub-cycle 3: family caregiver interviews

During the ARG’s reconnaissance discussions, a number of concerns were raised about how family caregivers understood dementia and the special care environment. It was also identified that SCU staff members struggled to form partnerships with family caregivers that could facilitate their involvement in decision-making and other care processes. To explore these issues further semi-structured interviews were conducted with family caregivers. Figure 11 summarises the group’s action plan.

**Figure 11 Action Plan 3**

**Concern:** Determine the perspectives of family caregivers about dementia, the special care environment and their involvement in care partnerships and decision making.

**Action Plan 3:**
Conduct semi-structured interviews with family caregivers of residents

**Monitoring:**
Record research group meetings to develop case notes
Researcher to keep fieldwork journal

**Data Sources:**
Research meeting transcripts and case notes
Family caregiver interview transcripts
Researcher’s fieldwork journal

**Analysis:**
Researcher responsible for first level analysis, followed by collaborative analysis with research group to yield shared understandings.

6.3.1 Plan

**Figure 12 Action Plan 3 – Family caregiver interviews**

As previously discussed in Chapter 4 an interview schedule (see Appendix 9) was devised in consultation with the group members. The schedule contained questions that explored what participants understood about dementia (prior to and following
their relatives’ admission to the SCU); the means by which participants acquired information/knowledge about dementia; and their experiences of having a relative with dementia and being involved in their relatives’ care (including decision-making processes). In addition, questions were also added about how family caregivers understood palliative care and whether they thought that it was appropriate for their relative. The recruitment of family caregivers occurred through a third party.

### 6.3.2 Take action and collect data

Nine family caregivers were approached by the third party recruiter. Each family caregiver was identified as the ‘person responsible’ for a resident who had been on the SCU for 3 months or longer. With the exception of one family caregiver, all others that were approached agreed to participate and in fact were enthusiastic to discuss their experiences and understandings.

Overall, eight semi-structured interviews were conducted with ten family caregivers. Two of the family caregivers were accompanied by their wives to the interview. These dyads were not excluded from the sample, as it was evident that they had shared experiences and understandings in relation to the person with dementia. The narratives of these paired participants did not differ from those of individual participants. The relationship of participants to residents is outlined in Table 19, as well as the length of time that the person with dementia had resided in the SCU. Data collection occurred over a three month period.

### Table 19 Interview participants, relationship to the resident and resident length of stay in the SCU at the time of interview

<table>
<thead>
<tr>
<th>Interview Participant</th>
<th>Relationship to resident</th>
<th>Length of resident stay in SCU at time of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Daughter</td>
<td>3 years</td>
</tr>
<tr>
<td>P2</td>
<td>Son</td>
<td>3 months</td>
</tr>
<tr>
<td>P7 and P8 (Husband and wife)</td>
<td>Son and daughter-in-law</td>
<td>3 months</td>
</tr>
<tr>
<td>P3 and P4 (Husband and wife)</td>
<td>Son and daughter-in-law</td>
<td>1 year</td>
</tr>
<tr>
<td>P10</td>
<td>Daughter</td>
<td>3 months</td>
</tr>
<tr>
<td>P6</td>
<td>Daughter-in-law</td>
<td>1 year 2 months</td>
</tr>
<tr>
<td>P5</td>
<td>Daughter</td>
<td>3 months</td>
</tr>
<tr>
<td>P9</td>
<td>Daughter</td>
<td>2 years</td>
</tr>
</tbody>
</table>
6.3.3 Analysis and evaluation

The following is a first level iterative/thematic analysis reported from the interview data. A more detailed account of data analysis techniques has been provided in Chapter 4.

6.3.3.1 Knowledge of dementia: lay understandings

Analysis of interview data highlighted that family caregivers’ knowledge of dementia was a critical issue. Most family caregivers demonstrated lay understandings about dementia, which were often based on personal experience and observation. For example, one participant recalled how her grandmother ‘had dementia for 20 years before she died and during the process lost her speech and…played with dolls’ (P9). Another participant explained her mother’s brain as a type of circuit board, and envisaged the dementia ‘like a cloud, going over it, short-circuiting every bit of movement, every bit of…memory’ (P1). This family caregiver understood the dementia as ‘corroding or overcrowding’ her mother’s brain, thereby rendering her mother’s thoughts as having ‘nothing to do with reality’. Yet another participant expressed his understandings of dementia with a sense of futility and the recognition that it would ultimately annihilate his father. He believed he understood the ‘basics’ about his father’s condition and stated: ‘[dad] hasn’t got a memory, he hasn’t really got a mind… he’s strapped in [a chair] most of the time… he’s stuffed, he’s stuffed in my eyes…he’s not there, he never will be (P3)’.

Some family caregivers were uncertain about how to categorise their relatives’ dementia. For example, one participant reluctantly stated: ‘...I don’t know if [dementia] would be an illness of such (sic)’ (P5). Rather, she postulated that her mother’s memory loss was due to her being ‘lonely’ and lacking ‘stimulation to keep her mind ticking over’. Other family caregivers were also uncertain about how to understand dementia in relation to Alzheimer’s disease. One participant stated, ‘yeah dad’s got dementia’ and following this posed the question: ‘that’s what [Alzheimer’s disease] is, isn’t it?’(P4). Another family caregiver clarified how she had come to consider her mother’s condition as something separate from Alzheimer’s disease. She explained: ‘... the only difference between Alzheimer’s and dementia is Alzheimer’s patients get physically and verbally abusive and mum doesn’t, so she’s got dementia. I figured that out for myself… (P1)’.
It was evident from the narratives of these family caregivers that they possessed limited understanding about biomedical aspects of the dementia.

### 6.3.3.2 Dementia as a terminal condition

The way in which family caregivers understood their relative’s condition had significant implications for how they considered the relationship between dementia and death. It was apparent that dementia was not conceptualised as a disease process that would cause or even contribute to the death of their relative. As such, the majority of participants discounted dementia as a terminal condition.

Reflective of limited biomedical knowledge, most family caregivers lacked an understanding about the progressive nature of dementia. For example, one family caregiver acknowledged that she could see her mother ‘getting worse’ (P9) as the dementia progressed, but at the same time was not confronted by rapid signs of deterioration. The insidious nature of the dementia trajectory made it difficult for family caregivers to identify dementia as a condition from which their relative would most probably die. Another participant’s comment highlighted this point when she stated: ‘...I mean you look at someone with cancer you can sort of see them deteriorating whereas dementia no, I can’t see it with mum...’ (P6). Consequently, there was a general perception that the death of the person with dementia would result from a sudden, catastrophic health event. For example one family caregiver argued: ‘...I don’t think [my mother] will die from dementia, I think she will die from a heart attack or stroke or something’ (P6). Another participant stated: ‘there would have to be another cause (of death) like pneumonia or stroke’ (P8). Indeed, some family caregivers asserted that there was ‘nothing wrong’ with their relative, largely discounting the dementia as a potential contributor to their relatives’ demise. For example one participant stated:

... She’s [mum] not on any medication, so apart from her mind, which probably is not real, real bad at the moment I could see mum living another 10 years even though she’s 80, cause she’s not on any blood pressure medication or anything like that (P8).

Another participant echoed the same sentiments when he claimed ‘... [Dad] has no medical problems, he’s never had heart problems; he’s got arthritis...a couple of minor things but no major ailments....he could live for a bloody long time’ (P2).
Family caregivers’ understandings of the dementia trajectory became all the more apparent through the questions they posed during interviews. For example: ‘Do people die from dementia?’ (P6), and ‘how can you die of dementia? All the neurons in your brain decide not to function...’ (P2). Such questions attest to the unrecognised and largely unknown aspects of the dementia trajectory. In contrast to the above accounts however, two family caregivers did consider their relatives’ dementia to be a terminal condition. Despite this acknowledgment one participant (P3) was unable to envisage the course of his father’s future deterioration, while the other assumed her mother’s death would be a sudden event. For example she stated: ‘I know Mum is going to die, ’cause once your brain stops functioning that’s it you die!’ (P1).

Overall, it was evident from family caregiver accounts that dementia was not understood as a terminal condition. Relying primarily on lay knowledge, participants had little understanding of the progressive nature of dementia and its relationship with death.

### 6.3.3.3 Understandings of palliative care

As the interviews progressed it became increasingly apparent that the way in which family caregivers constructed their understandings about dementia impacted on what type of care they considered as appropriate for their relative. Some family caregivers believed palliative care was a suitable approach for a range of medical conditions from which their relative suffered. However, dementia remained exempt from consideration. For example, P5, who did not consider her mother’s dementia as an illness, highlighted this perspective in her following account:

...I mean she [mum] came in with heart failure...her heart was beating slow...and because of...the buildup of fluid in her legs and the ulcers, the heart isn’t beating fast enough to move the fluid so, to me you know that should be palliative care.

P3 considered that palliative care might be useful for his father when he progressed to his final stages but further clarified: ‘I don’t really know’. While family caregivers’ understandings of palliative care varied, most of their understandings largely reflected traditional conceptualisations of palliation associated with ‘cancer’ and end-of-life care.
It was evident that family caregivers had given little consideration to the provision of palliative care for their relative. P10 explained that she had never considered dementia as a condition that would require palliation despite her own personal study and attendance at information workshops. She stated: ‘cancer you do, heart disease you do, you know there is a whole list of things that lead onto palliation but dementia, nope’.

6.3.3.4 Capacity/strategies to access information

Family caregivers’ lay understandings about dementia can in part be understood in relation to their capacity to access information and resources. While some participants were equipped with skills/knowledge that assisted them to locate information about dementia, the majority of family caregivers did not have such “know how”. As such, most participants described unstructured and ad hoc approaches to learning about the condition. For example, they reported: ‘I’ve found out [about dementia] along the way... sort of got bits and pieces of information’ (P3); ‘...learning mainly as we went along’ (P6); ‘...I learnt [by] what people (friends and colleagues) have been saying... as I have gone along’ (P5); and ‘...I’d read a little bit [about dementia] over the years’ (P8). With little capacity to locate information, participants also relied on opportunistic strategies to develop understandings. For example, one family caregiver (P3) explained that his chief source of information was ‘a brochure’, which he found by accident at a local pharmacy. Another participant recalled that her brother had once provided her with information ‘to say what dementia was’ (P1). However, without further assistance this family caregiver reported that she was not sure where to find such information and did not have the skills to access additional resources. Other participants relayed similar stories that referred to limited or absent engagement with information.

However, a few family caregivers did have the requisite skills and knowledge to locate information and resources prior to and early on in their relatives’ admission to the SCU. For example, one participant who had tertiary qualifications, explained how he actively sought information ‘from various people...[and] read a lot about dementia’ (P2). Motivated by what he described as ‘a background in research’, he contacted a range of support services, including an interstate behaviour advisory service and Alzheimer’s Australia. P2 explained that as a result of his research, he did not consider people with dementia as ‘insane’ but rather he described them as ‘worn down memory people’. Another participant (P10) who was a small business
owner had attended Alzheimer’s Australia support groups following her father’s
diagnosis. She accessed information in a variety of ways. For example, she ‘found
various articles in the newspaper...located...information on the internet and...tried to
talk as...much as possible’ about dementia with other people. A third participant (P9)
explained that she had ‘the capability’ to locate support groups and proactively seek
information, based on previous experiences of her father suffering a stroke and
subsequent dementia, as well as having three aunts with dementia. Despite these
participants’ ability to access information and resources, it was evident from their
narratives that they still struggled to understand key aspects associated with
dementia. Of the three participants outlined above, all of them failed to acknowledge
the link between dementia and death. When challenged with the concept of dementia
as a terminal condition, one of these family caregivers stated with surprise: ‘...I read
a lot, I read books, I read articles, I studied on the net, I attended workshops and I
never put those two together!’ (P10). Such findings place into question the ability of
family caregivers to develop accurate understandings of dementia, even when they
have been able to engage with a range of information and support services.

6.3.3.5 Availability of information and support from General Practitioners

During the interviews, family caregivers made little comment on the role of service
providers in assisting them to access information, with the exception of GPs.
Participants explained how their interactions with GPs (prior to and following their
relatives’ admission to the SCU) provided little relevant information to assist their
understandings about dementia. For example, at a time when one of the participants
was struggling to understand her mother’s behaviour, she recalled that the GP had
directed her take her mother ‘on outings and to day centres’ (P5), but did not provide
information which answered her questions. Indeed, some family caregivers
questioned the extent of knowledge that GPs had about dementia, considering the
scarcity of useful information with which they were provided. For example, one
participant (P2) felt that his father’s GP ‘was not really clued up’ on dementia
because he only mentioned ‘a few things’ that were of little assistance. Although
family caregivers could not articulate exactly what information they wanted to know
from GPs, they shared a definite sense that they did not feel prepared or generally
well informed about their relative’s condition or what to expect in the future.

Some family caregivers discussed how their GPs were largely inaccessible following
the admission of their relative to the SCU. For example, when one of the participants
was asked about his contact with his father’s doctor, he laughed and stated: ‘...never seen the bloke!’ (P3). Similarly, another family caregiver stated that ‘apparently [the GP] comes in every fortnight’ (P6) to see her relative, but she could not be sure about this based on her minimal contact. Another participant explained ‘...I’ve never spoken to [the GP]...he has been somewhat lax in returning phone calls [since her father’s admission to the SCU]’ (P10). It was evident that most family caregivers did not consider GPs as key collaborators about their relatives’ condition or care.

6.3.3.6 Understanding the special care unit: ‘a different world’

In addition to family caregivers’ limited knowledge of dementia, they also shared accounts that indicted they struggled to understand the special care environment. All of the family caregivers recalled that they were aware, prior to their relatives’ admission, that the unit was secure but had limited knowledge about the SCU beyond this. For example P5 stated ‘I yeah, I knew it was going to be a secure unit, but that was all, that was about it’. P10 described similar circumstances: ‘they just sent a note that it was the secure unit’.

Having little other knowledge of the special care environment, P5 explained that it was ‘quite a learning process’ when she first visited the SCU after her mother’s admission. For example, she recalled initially being shocked by what she encountered on the unit ‘... like a man...weeing in the corridor’. Acknowledging that such behaviours outside the unit would not be considered as a usual part of normal everyday life, she described the SCU as a ‘different world’. The implications of family caregivers having limited information about the special care environment was further evident through the language they used to refer to the unit and some of the care practices they observed. For example, P3 described his father as being ‘tied in’ a chair when referring to his father being restrained, while P2 described the SCU as ‘like a jail’, seemingly having little awareness that the unit was secure to ensure the safety of residents. The perspectives of family caregivers suggested that the SCU was an alien environment to them.

6.3.3.7 ‘On the outside looking in’: information and support from SCU staff

In addition to the issues discussed above, family caregivers’ narratives suggested that their interactions with SCU staff left them with a sense of alienation on the unit. According to some of the family caregivers, SCU staff rarely spoke to them. One participant (P3) described that he had ‘bugger all’ to do with staff and described his
interactions with them as largely informal and superficial in nature. For example, he stated: ‘Oh yeah we’d have a bit of a chat sort’ (P3). Most family caregivers considered that they were likely to be approached by nursing staff when there was a major problem with their relative. Apart from these circumstances, opportunities for information sharing were rare. One participant explained that ‘staff rang up’ when his father ‘fell over a couple of times’ (P2), but following these events there had been little communication. Another family caregiver expressed similar sentiments, stating: ‘I’d hear if there was a problem...if there was something really worrying them [staff]’ (P9). Not surprisingly, some participants held the impression that nursing and care staff had little desire to enter into ongoing dialogue with them, making comments such as: ‘they [staff] don’t want to communicate with you...’ (P8); and ‘they [staff] don’t really discuss, they don’t really come to us and say anything’ (P4). Through sheer necessity some participants explained that they actively sought information about their relative from staff. These participants asserted: ‘...If I want to know something I’ve gotta go and ask’ (P1); and ‘...they [staff] don’t really say anything unless you ask’ (P4). On the whole, family caregivers revealed an acute sense that staff would not invite them to discuss their concerns and when they did, often out of frustration, staff appeared seemingly disinterested in their concerns. One participant (P5) described the process of trying to access information but being constantly sidelined as a ‘vicious circle’, where she felt as if she was ‘intruding’. Another participant stated: ‘...you can’t get answers...they [care staff] just sort of turn their backs on you, like you’re not important’ (P1). Others explained how staff would ‘brush away’ (P4). One family caregiver added: ‘...I’d ask a question [about mum], they’d (staff) say, It is a dementia ward you know!’ (P5). The implications of this were that family caregivers did not consider that they were regarded as integral in a care-giving partnership with staff, but rather they felt like ‘outsiders’. One participant highlighted these sentiments most succinctly when she stated: ‘I don’t really think that they value what I have to say...you’re on your own.... I’m on the outside looking in and it really gets to me!’ (P1). It was evident from the interview data that family caregivers felt excluded and effectively silenced by staff who were reluctant to engage with them.

Although some family caregivers were frustrated with the above circumstances, most did not display animosity towards staff. Rather, participants seemed to accept the terms of engagement on the unit and negotiated them as best they could. A number
of family caregivers queried whether understaffing and workloads were issues that impacted on the capacity of staff to provide support. A range of comments indicated a relative absence of staff on the SCU. For example participants stated: ‘...sometimes it's hard to find somebody [on the SCU]’ (P8); ‘... you don’t see them (staff), you don’t see anyone really’ (P3); and ‘I can sit in [mum’s] room...for nearly an hour ... and not see a carer’ (P5). Further compounding these problems was the busyness of the unit. One family caregiver described staff as ‘run off their feet’ (P10) and highlighted that under those circumstances families ‘...tend to be a bit forgotten’.

6.3.3.8 The experience of decision-making

It was evident from the interview data that a cascade of issues shaped how family caregivers participated in decision-making processes for their relatives’ future and end-of-life care. Factors that had a profound impact on the capacity of family caregivers’ to fulfil their roles as surrogate decision-makers related to their lay understandings about dementia, their limited access to educational/informational resources, and inadequate support from GPs and aged care staff.

Family caregivers described their interactions with aged care staff about decision-making as cursory and superficial. Participants revealed that staff constructed questions about future care in relation to the occurrence of a sudden health event (e.g. heart attack, stroke), thereby reinforcing their own confusion about dementia as a terminal illness. For example, one participant (P3) explained that a staff member had asked him if he wanted his father to be resuscitated should he ‘have a major fall...or ...a bit of a heart attack’. Another family caregiver (P9) recalled that she was asked about ‘resuscitation’ if her mother ‘went into a coma’. Conspicuously absent from participant accounts were discussions about future care wishes in relation to a slow, progressive deterioration of their relative. Overall, family caregivers did not recall discussions related to decision-making about symptoms commonly associated with advancing dementia such as loss of appetite, inability to swallow or impaired mobility. When questioned, one participant explained that conversations initiated by staff were ‘not that specific...’(P3). From this perspective it is hardly surprising that the importance of palliative care in the context of progressive decline was largely unrecognised by family caregivers.

Decisions relating to residents’ treatment and their care at the end-of-life were considered by the majority of participants to be the responsibility of medical and
nursing staff. One participant explained that he would leave treatment decisions ‘up to the doctor’ (P7) if his mother’s condition deteriorated. Another family caregiver recalled having ‘signed some stuff…’ to indicate that staff would make care decisions if his father ‘had a stroke. or was dying’ (P3). He went on to explain, ‘Yeah [I] sort of only go by what they [staff] say, honestly we’re not doctors…yeah they’re the ones who are taking care of [Dad] really’ (P3). Indeed, there was a perception amongst family caregivers that health care professionals know best and as such decisions largely remained at the discretion of facility staff. Arguably, family caregivers’ tendency to delegate decision-making responsibilities to GPs and SCU staff also suggests that they were implicated in their own exclusion.

6.4.4 Reflection of ARG members: collaborative analysis of the data

Findings from the interviews provided rich ground for critical discussion between the ARG members. In some instances, they were affronted by narratives of family caregivers that revealed the disturbing implications of routinised care practices. Initially, as the ARG members reflected on the data, they reiterated concerns about what they perceived to be limited opportunities to interact and share information with family caregivers amidst heavy workloads and short staffing. Heather asserted that these circumstances had a profound impact on ‘time spent…talking’ with and ‘listening’ to family caregivers. Judy defensively stated:

...we can’t explain it all, we don’t have the time!...you know you get one [family caregiver asking questions] at twenty past eleven and [then] it’s ten to twelve, [and] it’s time to get down there [to the resident dining room] for medications....

However, as she reflected on the narratives of family caregivers that revealed their feelings of exclusion and alienation on the SCU, she conceded that staff members’ interactions with family were often ‘rushed. Building on this realisation, the group’s critical dialogues revealed their own collusion in maintaining dominant routines that failed to take account of family caregiver information and communication needs. It became evident to the ARG members that they prioritised habitual ways of practising by circumventing interactions with family caregivers who often lacked the requisite knowledge to understand changes in their relative’s condition. For example, Judy revealed how she knowingly avoided interaction with some residents’ family members who she described as ‘difficult’. She explained that there was not enough
time in her day to provide these family caregivers with information about the course of dementia, even though it may assist them to better understand their relative’s deterioration. Similarly, Heather highlighted that time constraints and heavy workloads resulted in meetings with family members being as she described ‘put on the back burner’. However, Judy explained that when these strategies failed and ‘anxious’ family caregivers continued to request of staff time that they perceived that they could not afford, these families would be referred to the resident’s GP for further information. Judy’s previously defensive stance diminished as she reflected on the emerging narratives of the group. Reflective of her changed understandings, she stated during a subsequent meeting ‘I suppose they [family] are excluded from care’.

In support of Judy’s perspective and consistent with the family caregivers accounts, Catherine and Elizabeth, the PCAs in the ARG, highlighted that they avoided substantive contact with family caregivers. Rather, they maintained brief and superficial communication with families. Elizabeth stated that these interactions were usually around social niceties, which she explained as ‘hello, how are you…mum is well…or mum hasn’t had a good night’. Catherine highlighted that nursing staff retained responsibility for communicating about the resident’s condition and care, even though this hierarchy of communication often frustrated family caregivers in their efforts to seek information. Nonetheless, Judy explained that such communication processes were necessary because they reduced the likelihood of PCAs being asked questions that they may not be able to answer and minimised family caregiver’s imposition on their time.

The group’s reflections on how interactions with family caregivers were constructed appeared to be strikingly similar to family caregivers’ narratives about their experiences. Indeed, one family caregiver’s reference to the ‘vicious circle’ of trying to have her concerns addressed and being frequently avoided, emerged in the group’s critical encounters as the status quo of communicative practices in the SCU. It became increasingly evident to the ARG members that their previous claims about centrality of family caregivers in care processes could at best be described as rhetoric. Judy asserted, ‘there is just not that support for the families’, which supported this change in the understanding. Thus, the group members agreed that they had a responsibility to address the information and communication needs of families.
When reflecting on the family caregivers’ narratives that revealed their limited understandings about dementia, palliative care and the special care environment, the group members recognised an imperative to make available ‘basic information about dementia, what [to]... expect as the disease progresses and what to expect...when going to a dementia-specific area’. While they recognised that providing such information was not going to address all of the issues that had been identified, they surmised that this could be a step towards more positive engagements with family caregivers in the future. However, reflective of an absence of infrastructure at the facility to support family caregivers, I questioned the group about the presence of information booklets, leaflet or pamphlets on the SCU. Each group member stated: ‘I've never seen anything!’ To this end, the group members devised a focus for action: to locate formal resources and provide family caregivers with information addressing key issues associated with dementia, palliative care and the SCU. Planning activities specific to the action are explicated in Chapter 8.
6.4 Sub-cycle 4: critical dialogues with key staff

Concerns that underpinned sub-cycle four emerged from the reconnaissance discussions which revealed a fundamental contradiction between how palliative care was conceptualised and actualised in practice. The ARG members planned to further explore this issue through critical dialogues with other key staff. Anne asserted that it was important to know what other staff ‘think’ about palliative care and what sort of contradictions they might experience in their practice. According to the ARG members such concerns had not previously been given substantive attention nor had staff members’ experiences of talking about death and dying. Therefore, through the critical dialogue the group members hoped to gain further insights into how palliative care was operationalised in the SCU.

Figure 13 Action Plan 4

**Concern:** ARG members want to further explore the dissonance that they discovered between their conceptualisations of palliative care and how they operationalised it in practice.

**Action Plan 4:**
Explore how staff members conceptualise and provide palliative care through the conduct of critical dialogues with key staff

**Monitoring:**
Record research group meetings to develop case notes
Researcher to keep fieldwork journal

**Data Sources:**
Research meeting transcripts and case notes
Transcripts of critical dialogues
Researcher’s fieldwork journal

**Analysis:**
Researcher responsible for first level analysis, followed by second level collaborative analysis with research group.

6.4.1 Plan:

Figure 14 Action plan 4 – Critical dialogues with key staff
As reported in Chapter 4, key questions were devised in the context of the ARG meetings. Through the critical dialogues, group members wanted to explore how other staff understood palliative care in the SCU, whether staff considered it as something different from their every-day practice and whether dementia was understood as a condition for which palliative care was applicable.

6.4.2 Take action and collect data

I encountered a number of issues in recruiting staff to participate in critical dialogues. Overall, four staff members from the SCU and two GPs were recruited. As highlighted in Chapter 4, two GPs agreed to participate. They provided care for approximately one third of the residents in the SCU and had been visiting the unit for between 5 and 10 years. The sample of SCU staff consisted of two PCAs, one EN and one allied health (AH) staff member. I was unsuccessful in recruiting any RNs to participate in the interviews. In addition to Judy and Heather, there were only another two RNs who worked regularly in the SCU; and neither responded to invitations to participate. In addition to Anne, there were three ENs who worked regularly in the SCU, one of which agreed to participate and had extensive experience working on the SCU. One AH staff member was recruited out of a possible four staff. As shown in Table 20 participants had a cumulative experience of almost 30 years working on the SCU. With the exception of the allied health staff member, the other participants had completed the questionnaires for Action Plan 1.

Table 20 Critical dialogue participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Time spent on the SCU</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enrolled Nurse - EN</td>
<td>&gt;10 years</td>
</tr>
<tr>
<td>Personal Care Assistant - PCA1</td>
<td>3 to 5 years</td>
</tr>
<tr>
<td>Personal Care Assistant - PCA2</td>
<td>&gt;5 years</td>
</tr>
<tr>
<td>Allied Health (AH) Staff member</td>
<td>&gt;10 years</td>
</tr>
</tbody>
</table>
6.4.3 First level analysis

6.4.3.1 Understandings of palliative care

The narratives of participants revealed that palliative care was integral to everyday care for residents. While participants did not specifically talk about a ‘palliative approach’ (ADoHA, 2006) they illustrated knowledge about some of the key principles underpinning contemporary notions of palliative care. They shared understandings of palliative care as proactive, needs-based, and holistic care appropriate for people with dementia. For example, GP1 argued that the SCU functioned as a type of de-facto hospice when he suggested that the ‘whole care’ of residents ‘is palliative’, acknowledging that the majority of residents will die on the unit. Thus he asserted that the ‘prime focus’ was on ‘patient and family comfort’. GP2 shared similar sentiments when he described palliative care in terms of supportive management rather than more aggressive care. He stated: ‘... it’s more treatment of the episodes as they occur...minimising medications as much as possible...in a sense it might be more of what you don’t do, rather than what you do do’.

The SCU staff members shared understandings of palliative care as being focused on the needs of residents rather than on the stage of their condition. For example, the EN emphasised: (palliative care) ‘is ...going down that broader approach... not just end stage’. Similarly, PCA2 stated:

\[I don't feel that palliative care is basically for people who are ... on their way to heaven... I think palliative care is for... a different mix of people at different stages.... I think palliative care is when it’s needed.\]

Palliative care was also understood as ideally implemented in a proactive manner. For example, PCA1 commented that ‘palliative care starts when the resident walks through the door’. The AH staff member also emphasised palliative care as maintaining a holistic focus on ‘the needs of the whole person’ (e.g. spiritual, physical, psychological and social).

Even though participant accounts suggested that palliative care was fundamental to the everyday activities of resident care, as their narratives unfolded a number of contradictions emerged between how staff members conceptualised palliative care and how it was actualised in practice.
The narratives of participants suggested that there was at best limited staff engagement with palliative care, death and dying. Both GPs struggled to provide examples from practice which would illustrate a reciprocal dialogue with other staff in the SCU about palliative care. Rather, GP2 stated ‘...there is not...much discussion in my experience’. Given that the GPs had previously highlighted the importance of palliative care for residents, I questioned them about how they understood their role on the unit. Their responses suggested a technical approach to resident care. Both GPs described their roles as focusing on the practicalities of providing medical care to residents. GP1 suggested that his priorities were on ‘day to day’ management of medical events such as: ‘the lady with the abdominal pain and vomiting and the fever ... which needs to be treated and the fella who falls who gets the [fractured] neck of femur’. These examples related to acute interventions in response to crisis events rather than palliative management. GP2 asserted that another key aspect of the medical role was to ensure that relevant documentation was attended to. He explained that ‘...the medical role is to ensure to make some notes... our actual minimal requirement is really the drug chart and...organising the prescribing...’. He went on to argue that he occupied a role in the SCU as ‘strictly a medical function rather than a more global...sort of input’.

Both GPs highlighted that the demands associated with heavy workloads and workforce shortages of GPs constrained their capacity to provide care beyond the basic medical necessities. GP2 asserted that ‘there is [sic] only so many hours in the day’ and the introduction of remuneration incentives to encourage more sustained involvement in resident assessment and care planning did little to alleviate the excessive work demands. As a result he acknowledged that he had limited accessibility to aged care staff, residents and family caregivers. The implications of episodic involvement in care were apparent when GP1 stated that ‘issues about [the residents’] departure’ were usually not addressed until they were ‘on the slide’ towards death.

Like the GPs, both PCAs highlighted that conversations about palliative care were scarce on the SCU. PCA2 claimed that she had also ‘never discussed’ issues related to palliative care for residents with any of her colleagues. The EN asserted that talking about death was not a usual occurrence in practice and went on to state that staff have ‘a lot of problems’ with using the word ‘die’. The AH staff member
supported this perspective when she stated ‘some staff will say to me “don’t say die”’, explaining that they found such language confronting. These accounts, which highlighted the avoidance of conversation amongst staff members about palliative care and death, sat in stark contrast to their earlier understandings of palliative care as proactive and holistic. For example, PCA1 recalled that after almost three years working on the unit, she was only recently involved in a discussion about the death of a resident. She stated: ‘...that was the first time I actually talked about someone dying and all the rigmarole that goes with it... and someone’s finally said something, it’s amazing!’.

It was apparent from participant narratives that the priorities of practice did not include discussing issues of mortality. The EN, PCAs and to a lesser extent the AH staff member indicated a predominately task-orientated approach to providing care to residents. For example, the EN stated that her primary responsibilities centred on ‘doing the pills’ for all residents twice each shift as well as other technical tasks such as attending to wound care and assessment documentation. The two PCA staff described the bulk of their role as providing ‘physical care’ to residents, such as showering, feeding and toileting. PCA2’s description of her practice as having ‘x amount of people to look after ...[and] x amount of time to do it in’ is suggestive of a task-oriented approach to resident care. Staff members’ accounts illustrated how these circumstances impacted on the opportunity and ability of staff members to engage in dialogues about palliation for residents.

The AH staff member highlighted that material conditions such as inadequate staffing and resource constraints had a ‘big, big’ impact on the ability of SCU staff to actually find time to talk about death and to support residents and their family caregivers. Similarly, the EN shared concerns about a lack of appropriate infrastructure at the facility to support staff to talk openly with each other about death, dying and palliative care. She argued that processes such as formalised debriefing sessions, needed to be embedded into the functioning of the unit to facilitate such a dialogue. In the absence of such processes the EN argued that the practices of staff members on the SCU would continue to be task-oriented with little acknowledgment of dying.
6.4.3.3 Disparate connections between dementia and death

The relationship between dementia and death also seemed unclear for some participants. For example, PCA2 asserted that despite knowing that people with dementia do ultimately die she had ‘never thought of dementia as a terminal condition...’. When PCA1 was asked about her perceptions of dementia she stated that she did not consider people with dementia as having a terminal condition and asserted: ‘I think of them as normal people with a problem ... I don’t think of them over all as people are dying. I mean they have specific needs and problems and I’ll deal with them on that day’.

The EN considered the notion of people dying from dementia as ‘an interesting concept’, and went on to suggest that her reaction was indicative of having not previously considered dementia as a terminal condition. GP2 stated, ‘...I wouldn’t normally consider someone has a terminal condition if they have dementia’. While GP1 agreed that people with dementia would at some stage progress to a terminal phase, his accounts suggested that he did not consider it as an ‘obviously malignant, progressive process’. During the dialogues with GPs, neither indicated a willingness to talk about dementia as a terminal condition. PCA1 suggested staff maintained a type of dissonance around how death and dementia were conceptualised, stating: ‘...we know they’ll [residents] die in the back of our mind...but you don’t try and associate with it too much...’. With interactions between staff members not explicitly acknowledging the connection between dementia and death, PCA1 argued that for care staff palliative care was not recognised as an integral component to their practice when she stated: ‘...care staff think palliative care that’s about death and dying that’s got nothing to do with us, let’s get on with our job...’.

On the whole, the dialogues indicated that the relationship between dementia and death was at best ambiguous and for some non-existent.

6.4.3.4 Rhetoric and reality: the operationalisation of palliative care

The narratives of the GPs and SCU staff members were at times convoluted with respect to how they understood palliative care and how they actually translated these understandings into practice. For example, contrary to the narratives suggesting that a palliative approach to care was adopted from the early stages of the resident’s stay in the unit; SCU staff illustrated that palliative care was implemented in a reactive, rather than proactive manner. For example, the EN accounts of practice revealed that
if a resident was ‘up and about and walking and talking even though it might be demented gibberish...’ they would not be at the stage of needing palliative care. Rather, she suggested that palliative care would usually be implemented when a resident’s dementia ‘progresses’ into more advanced stages, which PCA2 later clarified as the resident being ‘bedridden’. Further suggesting the operationalisation of palliative care as synonymous with terminal care, PCA2 highlighted that there was little documentation to support staff to implement a palliative approach prior to the end-of-life, she stated: ‘there’s often not a lot about palliative care in the care plan...nothing is written up on palliative care until you get there (end of life)’. In support of this account, the EN indicated that it was not unusual for nursing staff to feel uncomfortable raising issues associated with death and palliative care. She explained that she would usually ‘brush over’ these topics with family caregivers if the resident showed no indication that they were likely to die in the near future, adding that such communication ‘is not necessarily proactive’ and ... ‘it’s...something that comes up when they’re [the resident] heading sort of towards (death)...’. While the AH staff member shared aspirations of talking with family caregivers ‘early’ about their relatives’ conditions, she conceded that in the absence of an integrated and structured approach adopted by the whole organisation, her interactions tended to occur opportunistically and therefore it was not uncommon that these conversations occurred at the end-of-life stage.

In keeping with the above findings, GP1 explained that his role in the provision of palliative care in the SCU was to facilitate residents’ ‘exit from life in the most kind and humane way’. Both GPs suggested that their discussions with family caregivers about the role of palliation occurred in the later stages of the resident’s condition. For example GP2 stated: ‘to be honest I don’t often have a lot of contact with them [family] until things are getting pretty, you might say more terminal’. Similarly, GP1 argued that in his opinion family caregivers ‘don’t...really want to know what’s inevitable...don’t want to acknowledge that dementia can be [sic] a terminal illness...’.

During their dialogues the GPs raised conjecture as to who had the responsibility for initiating discussions about palliative care with family caregivers. GP2 implied an understanding that such discussions were in the mandate of the nursing role, asserting that he had ‘never been invited’ by nursing staff to participate in any such care planning meetings with family. Yet, GP1 appeared more uncertain about the
process and questioned ‘who’s got the experience to do that?’.

These accounts suggest that proactively engaging with family caregivers or staff about palliative care planning was not considered a priority or a necessary part of the GP’s role. The critical dialogues highlighted that palliative care on the SCU was operationalised as end-of-life care, suggesting that claims about palliative care in the SCU as proactive, needs-based, holistic care were more rhetorical than realistic. On the contrary, practice was structured around a functional approach to resident care, where staff roles were clearly demarcated according to a predominately task oriented focus. The disjuncture between how palliative care was conceptualised and operationalised in the unit was an issue also raised by the research group and it highlighted how the provision of palliative care on the unit was shaped to a large extent by the conditions under which staff practiced.

6.4.4 Reflection of ARG members: collaborative analysis of the data

As the group members reflected on the critical dialogues of staff, they recognised (similarly to their reconnaissance discussions) that a number of contradictions existed between rhetorical understandings of palliative care and its operationalisation in practice. Data indicating the limited dialogues between care staff, nursing staff and GPs regarding death and dying caused the ARG members to consider their own preparedness to broach these issues. For example, Anne highlighted that she felt ill-prepared to facilitate sensitive discussion about dying and death. She stated: ‘...I don’t know how much to say, because what is right?’.

On further reflection, Anne added that talking about death was ‘socially not accepted’. Judy shared parallel concerns with respect to her interactions with family caregivers when she claimed ‘you don’t know what to say’. At this point, Judy and Anne (nursing staff) queried whether actually initiating discussions with family caregivers about palliative care was in fact their responsibility. Judy argued that it was the GP’s domain, stating ‘I think it is up to the Doctor...’. She went on to explain that it was ‘very hard’ for nursing staff to talk with relatives of a newly admitted resident about palliative care, as they had limited time for any substantive contact. However, Anne suggested it was the responsibility of family caregivers to initiate ‘a meeting with [the resident’s] GP’ to discuss issues related to future care and treatment options. The somewhat differing perspectives among group members suggested that a clear understanding of the responsibilities of family caregivers, GPs and for that matter the group members themselves in relation to palliative care planning was lacking.
It was apparent from the discussions that the nursing staff were reluctant to accept responsibility for initiating communication about palliative care. Somewhat frustrated by the blame-shifting on this issue between nursing staff and GPs, the PCAs in the ARG pointed out that without greater clarity on people’s respective roles, family caregivers and residents were at risk of receiving inappropriate care. For example, Elizabeth recalled an incident when, in the absence of a clear strategy for managing the care of a dying resident, the decisions of SCU nursing staff and the GP contravened the wishes of the family caregiver. Given that no staff member (nursing or GP) had formally discussed or documented the family caregiver’s wishes, Elizabeth explained that the resident was transferred to hospital only to be returned the same day with no changes to her care. Catherine stated: ‘the family caregiver was not happy that her mother was transferred...she didn’t want mother to go to the hospital’. According to Elizabeth, the family member considered the events so distressing and traumatic for her mother that she asked about the possibility of euthanasia, stating: ‘I just want it to end for my mother now, what do I do?’ This story was a powerful account that prompted the group members to reconsider their responsibility to improve palliative care planning activities in the SCU.

Suggestive of changes in their understandings the group members recognised an imperative for SCU staff to be more proactive and adopt a leadership role in initiating discussion about dementia, death and palliative care practices with family caregivers. Hence, Anne acknowledged: ‘yeah we are responsible’ and Heather agreed stating: ‘the buck stops with us doesn’t it’. Likewise, Judy agreed that nursing staff ‘have the predominant role’ to play in facilitating family caregiver involvement in decision-making for their relative’s care. There was consensus amongst the group members that a greater focus on collaboration with family caregivers was crucial to providing them with an opportunity to proactively engage in shared dialogue and decision-making. Anne stated:

\[I \text{ think something like [case conferences] would be very useful and then it’s done at the beginning [of the resident’s stay]...they are not dying they have just come [to the SCU]...lets talk about it as a family, [the resident] is not dying, so there is not that anxiousness about it.]

Heather stated with a sense of frustration that in the ‘last 10 years’ she had only attended ‘one case conference’ at the RACF where nursing staff, the GP and the resident’s family had engaged in care planning discussions. However, excited at the
prospect of implementing change she asked: ‘end-of-life planning...how soon can we incorporate something like that here?’. Subsequently, the group members identified a focus of future action: to investigate the possibility of conducting palliative care planning case conferences with family caregivers. Initial planning discussions are outlined in Chapter 8.

6.5 Discussion

Street (2004, p.332) has argued that for action research to be effective, it is essential that baseline data collection is able to “articulate the complexity” of the problem(s) under investigation. During this first action cycle, a “multifaceted baseline” (Street 2004, p.332) was established through collection of qualitative (interviews and critical dialogues) and quantitative data (questionnaires and audit). While the ARG members had access to a plethora of data, generated in sub-cycles one to four, they made a strategic decision to focus on key findings that further explicated concerns raised in the reconnaissance. The group members participated in over 11 hours of research meetings to identify four areas in need of change and improvement, these being; i) staff knowledge and understanding about a palliative approach to care, ii) family caregiver information and support, iii) issues with palliative care planning, and iv) issues with pain assessment and management.

The first set of data returned to the ARG members was from staff questionaries that were administered in sub-cycle one. Eighty-eight per cent of permanent staff returned the questionnaires, providing a relatively robust sample of the characteristics of those caring for residents, including their educational backgrounds and knowledge about a palliative approach and dementia. The sample was typical of the Australian RAC workforce in terms of age (Martin & King 2008). However, they were atypical in terms of job tenure and educational qualifications. According to the most-recent national data on the aged care workforce (Martin & King 2008, p.20) 28.4% of people have worked in the sector for six of more years; the proportion of our sample that worked in RAC for the same duration was almost two and half times larger. Additionally, almost 80% of the direct care staff in this study had qualifications relevant to their job, which was markedly higher than national data (Martin & King 2008) for the same group. A likely explanation for this finding is that the aged care provider at that time was also a Registered Training Organisation that provided financial support to PCA staff from the facility to undertake Certificate III and IV aged care qualifications. However, with the exception of one EN, all
nursing (n=8) respondents were hospital trained. This did not represent national data (Martin & King 2008) which has indicated a rising proportion of degree-qualified RNs and diploma or equivalent Certificate IV-qualified ENs. Only one service staff member had a related post-secondary qualification.

Demographic data collected in sub-cycle one indicated that most of the nursing staff (86%) and direct care staff (70%) had previously attended some sort of formal education about dementia (e.g. in-service or external training). While aged care literature has reported low levels of dementia education amongst nursing and care staff in Australian RACFs (Doyle & Ward 1998), it is pertinent to note that following the announcement of dementia as a National Health Priority in 2005, dementia education and training was rolled out across the aged care sector in Australia (Fleming & FitzGerald 2009). The conduct of this education may explain why the majority of respondents reported having undergone formal education. While no nursing or direct care staff had formal qualifications in palliative care, consistent with the findings of others (Grbich et al. 2003; Clare & De Bellis 1997; Whittaker et al. 2007), approximately three-quarters of the respondents indicated that they had attended education sessions or short courses, usually run by a specialist palliative care service. This finding is consistent with earlier Australian research (Grbich et al. 2005), however, due to limitations in the data collected, any further disaggregation of participant responses about when and how often formal education had been attended was not possible. None of the service staff (n=6) from the SCU had attended any formal education about dementia or palliative care. While the preparation of ancillary workers has been identified as an important concern that warrants further investigation (McInerney et al. 2009), it was not within the scope of this study. The following discussion will therefore focus predominantly on data from nursing and direct care staff.

The reflections of the ARG members provided valuable insights about issues that influenced their educational preparation. Consistent with concerns in the literature (Froggatt 2000a; Abbey et al. 2006), the group members highlighted problems with the relevance and appropriateness of education provided by specialist palliative care services. They claimed that education often had a focus on issues related to the care of people with malignancies, rather than a more generalist palliative approach for people with non-malignant conditions, such as dementia. Additionally, problems with accessing education were also raised and the group’s reflections revealed that at
best SCU staff had episodic engagement with palliative care education, an issue also identified in the aged care literature (Phillips et al. 2006; Allen et al. 2008; Brazil & Vohra 2005; Maddocks et al. 1996; Whittaker et al. 2007). These findings support perspectives of others (Avis et al., 1999; Froggatt et al., 2002; Hasson et al., 2008; Phillips et al., 2008) that aged care staff are isolated from palliative care education and expertise. The accessibility to education more generally in the sector (Moore & Haralambous 2007; Fleming & FitzGerald 2009) is an issue that has been frequently highlighted as limiting the capacity of staff to develop evidence-based practice.

Given that most nursing and direct care staff from the SCU had attended formal education about palliative care at some point may explain findings from the PAQ that indicated most respondents had an elementary level of understanding about contemporary palliative care. Consistent with the literature (World Health Organization 2002; Addington-Hall & Higginson 2001; ADoHA 2004; Kristjanson et al. 2003; PCA 2005b), respondents indicated a palliative approach to be multidisciplinary, holistic, individualised, applicable to people with dementia and appropriate when a person was having active treatment. The qualitative accounts from staff members (GPs, n=2; EN, n=1; PCAs n=2, allied health n=1) who participated in critical dialogues also complemented these findings. However, as will become evident in the following discussion, staff understandings about how to operationalise a palliative approach (e.g. who could implement it and when it could be implemented) were problematic.

Firstly, findings from the PAQ revealed that half of the nursing staff (n=8) who worked regularly on the SCU incorrectly identified that the implementation of a palliative approach was dependent on a referral from a doctor. This finding is concerning because nursing staff in RACFs are positioned as clinical leaders, responsible for directing care provision (Jones et al. 2002). They are identified as having a central role in the initiation and implementation of a palliative approach (Phillips et al. 2006; Shega et al. 2003) and end-of-life care (Ersek et al. 1999). The reflections of the ARG members revealed their complicity in supporting dominant medical agendas, through their taken-for-granted reliance on GPs to initiate a palliative modality of care. Parker and De Bellis (1999) pointed out that the transition of residents in aged care facilities to palliative care has historically been in the remit of medical decision-making. Further reflective of this hierarchy, it is reported that GPs are the first point of contact for nursing staff to access palliative
care expertise (Katz et al. 1999; Komaromy et al. 2000; Parker & De Bellis 1999; Maddocks & Parker 2001) and provide referrals to specialist palliative care services for further consultation (Parker et al. 2005).

A reliance on GPs to initiate palliative care has been suggested as problematic (Hanson et al. 2002; Wowchuk et al. 2007). GPs have been found to have variable levels of knowledge about dementia as a terminal condition (Parker et al. 2005; Dharmasena & Forbes 2001) and have difficulty knowing when a palliative approach is warranted (Avis et al. 1999; Mount Olivet Community Service Ltd 2003). Moreover, as previously highlighted by the ARG members in the reconnaissance (Chapter 5) and in other studies (Phillips et al. 2006; Travis et al. 2002), RACF staff have difficulty accessing GPs. This situation was confirmed by the GPs (n=2) that participated in the critical dialogues, when they reported episodic involvement in resident care and suggested that their practice was predominantly constructed around technical activities, such as the completion of drug charts and medical notes. The GPs’ accounts support previously identified concerns (Shipman et al. 2001; Mitchell, 2002; Mount Olivet Community Service Ltd 2003; Field & Froggatt 2003; Avis et al. 1999) about the impacts of inadequate resourcing and workforce shortages that can result in inequitable medical input for people in aged care settings (Glendinning et al. 2002). Despite these problems, the reflections of the ARG members suggested that nursing staff were complicit in supporting medical dominance over decision-making concerning the palliative status of residents in the SCU. Street (1992) argued that nursing’s “non-critical acceptance” (p.42) of the “hierarchical ordering of knowledge” (p.39) that situates medical knowledge as superior, sustains dominant power relations. Indeed nursing’s privileging of medical interests have been reported across a variety of nursing contexts, resulting in the needs of vulnerable older people not being adequately addressed (Stratton 2009; Street 1992).

In addition to the above issues, the capacity of direct care staff in the SCU to provide a palliative approach to care could also be questioned. Findings from the PAQ indicated that one third of these staff (n=23) incorrectly believed a palliative approach to care needed to be delivered by staff with specialised qualifications in palliative care. In support of this finding, the critical dialogues conducted with PCAs (n=2) highlighted that care staff struggled to have an appreciation of their role in delivering a palliative approach and in some cases did not consider palliative care as part of their job. This finding supports the literature (McDonnell et al. 2009; Ersek et
al. 1999) highlighting that direct care staff are not adequately prepared to deliver palliative care and without appropriate support, may have trouble integrating and understanding it as part of their everyday practice (Holman & Crowhurst 2009). Moreover, it also reflects what Foucault (1980b, p.133) might call a “regime of truth”, wherein staff members’ assumption that the delivery of palliative care is reliant on “expert knowledge” (Foucault 2002, p.132) sustains medical dominance and limits staff from recognising their ability to provide a palliative approach in the context of everyday practice. This is perhaps not surprising given that until the early 1990s palliative care was a medical specialty, separate from mainstream medicine (Kindlen & Walker 1999; Finlay & Jones 1995). Finlay and Jones (1995, p.754) have suggested that this historical separation has led to uncertainty about the “legitimate province” of palliative care in locations such as RACFs. With the critical dialogues of SCU staff indicating that their practices were constructed around technical care tasks and routines, the ability of staff to conceptualise their practices in the framework of a palliative approach is bounded by their knowledge and practices which support an “instrumental” care culture (Tuckett 2005, p.220).

In consideration of the aforementioned findings, the data also suggested that SCU staff held traditional understandings about palliative care. Most nursing and direct care staff indicated on the PAQ that a palliative approach was synonymous with terminal care. This finding was confirmed in the literature (Maddocks et al. 1996; Komaromy et al. 2000; Whittaker et al. 2007). Recent research (McInerney et al. 2009; McDonnell et al. 2009) has revealed that RACF staff, in particular PCAs, understand palliative care as a euphemism for care at the end-of-life. The critical dialogues confirmed that the participants generally did not consider dementia to be a terminal condition but did consider palliative care as appropriate for people with dementia at the very end-stage of the condition. This finding is perhaps not surprising given that the majority of SCU staff incorrectly indicated on the KDQ that memory loss was as a normal part of ageing. Previous research (Hsu et al. 2005) has highlighted the lack of knowledge of aged care staff with respect to mental health. While other research has suggested that health care professionals in general are poorly informed about dementia (Barrett, Haley & Powers 1997) and that memory loss is not a normal ageing event but a result of underlying pathology (Hughes et al., 2008). While overall the results from the KDQ indicated that staff had a good basic knowledge of dementia, a finding that may be a consequence of the national dementia education campaign (Fleming & FitzGerald 2009) their understandings of a
palliative approach as being proactive and dementia being a terminal condition were important areas of knowledge deficit.

In recognition of the need to investigate strategies to facilitate staff access to appropriate education, the ARG members shared an emerging awareness that they were disengaged from evidence that could support the implementation of a palliative approach on the SCU. The group’s critical reflections revealed that they were essentially passive recipients of information from more senior members of staff. Their unexamined dependency on facility management can be understood as supporting the hegemony of institutional interests. Drawing on Foucault’s conception of power/knowledge, Gaventa and Cornwall (2001, p.74) have argued that when people are excluded from access to knowledge and participation in its production, the boundaries of their action are prescribed by the dominant interests of others. From this perspective, the capacity of ARG members to exercise power to pursue more holistic care agendas and in doing so challenge the status quo of routine task-oriented practices was minimal. Indeed, their lack of awareness about the Guidelines (ADoHA 2006) or the Standards for Pain Management in RACFs (APS 2005) is suggestive of the absence of an evidence-based care culture in the SCU.

The dominance of managerial and resource-led interest over an evidence-based practice agenda was evident when Heather reflected on her inability to champion the implementation of the Guidelines (ADoHA 2006) at the RACF. She conveyed a sense of powerlessness to challenge the boundaries of her existing practice, citing that institutional agendas did not prioritise resourcing implementation activities. This finding, similar to that of Robinson, Andrews and Fassett (2007), suggests that aged care staff struggle to support innovation within a network of hegemonic power relations. With new understandings of how their uncritical and unexamined reliance on management had failed to support their interests in improving resident care, the ARG members recognised the need for action aimed at broadening staff members’ knowledge of a palliative approach and of the Guidelines (ADoHA 2006). This focus for action reflected a shift in the group’s position from their previously more passive roles.

Further, the operation of dominant power relations in the SCU was evident in problems with establishing a supportive environment for family caregivers. The reflections of group members suggested that they unwittingly exercised power to restrict family caregivers’ access to them. Their accounts of avoiding family
caregivers or deferring them to GPs were similar to reports of aged care staff employing technical strategies to keep family caregivers “at a distance” (Bauer, 2006 p.49). The group’s reflections suggested that their actions supported imperatives of organisational efficacy with limited disruption to staff routines. However, remaining “ensconced in a task-focused model of care” (Bauer 2006, p.51) marginalised family caregivers’ needs for information and support.

It was evident from the interviews with family caregivers that they had predominately ‘lay’ understandings of dementia and consistent with Chung (2000), they had little knowledge about the trajectory or the progressive nature of dementia. Moreover, the majority of family caregivers were unaware of the relationship between dementia and death, and reported minimal interaction with SCU staff around this topic. Family members postulated that a sudden medical event (heart attack, stroke) would be responsible for their relative’s demise. These findings are consistent with other qualitative research (Forbes et al. 2000; Shanley & Whitmore 2008; Gessert et al. 2001) highlighting the challenges faced by family caregivers in their attempts to make sense of dementia and be involved in care processes. The traditional hierarchical model of staff-family caregiver relationship positions nursing staff as the “experts”, in control of decisions about care provision (Levine & Zuckerman 2000). However, within the hegemony of institutional interests the ARG members’ reported feeling powerless to prioritise family-focused needs, the implication of which was manifest in family caregivers narratives of feeling like ‘outsiders’ and of what others (Levine & Zuckerman 2000; Bauer 2006) have referred to as peripheral to care processes. The findings of this study supports previous work highlighting the imperative for care to be shaped in ways that include family members as partners with aged care staff in caregiving (Nolan et al. 2002a; Nolan et al. 2004; Davies et al. 2007). There is a crucial need for aged care staff to reconfigure their care practices to promote opportunities for “regular interaction” and the development of “reciprocal relationships” with family caregivers (Brown Wilson et al. 2009).

By having the opportunity to reflect on the narratives of family caregivers, the ARG members revealed, albeit briefly, new insights into how their situation could be different. These insights stemmed from an emerging recognition of the rhetoric inherent in claiming that family members were central to practice on the SCU, when in fact data from the interviews and their critical reflections clearly suggested
otherwise. Herein, consistent with White (1995, p.20) an “alternative” narrative emerged through the group’s critical dialogues. The ARG members could no longer view family caregivers’ knowledge deficits or their feelings of alienation on the SCU as a problem that was external to them. Demonstrative of a new sense of responsibility, they considered action aimed at reconstructing their practices to better meet the information needs of family caregivers. In doing so, the ARG members sought to challenge the “functional rationality” (Kemmis 2001, p.97) that shaped their care practices.

The dominance of managerial-led interests emerged again within the ARG’s discussion as they reflected on data indicating the absence of communication with family caregivers about dying and death of their relative. This issue became the focus of the group’s reflection when they were considering the audit findings from the ACP domain. These findings indicated that there was an absence of ACP meetings with family caregivers and a lack of individualised resident information in resident files that could direct care towards the end-of-life. Other studies also confirm low frequencies of advance care plans for people in RACFs (Nair et al. 2000; Grbich et al. 2003) and in general limited planning activities in long-term care environments (Bradley et al. 1998; Nair et al. 2000; Happ et al. 202; Forbes et al. 2000; Froggatt et al. 2008; Shanley et al. 2009). Moreover, palliative care documentation located in the audit was, as others have reported (Grbich et al. 2003; Grbich et al. 2005; Nair et al. 2000; Shanley & Whitmore 2008), poor quality and comprised repetitive, generic statements that would be of little use in directing care practices when a resident’s condition deteriorated. Initially, as the ARG members reflected on these data, they raised concerns about the content of the “palliative care planning form” used at the facility; arguing it failed to capture targeted information about the wishes of family caregivers. The lack of detail on the form can be understood as reflecting an organisational culture that did not acknowledge dying and death in a formalised manner. However, the subsequent reflections of ARG members also suggested their perfunctory acknowledgment of dying.

Nursing staff in the ARG revealed that their generic and repetitive palliative care documentation was constructed to satisfy regulatory/institutional documentation requirements, with limited imposition on their time. The privileging of “ritualistic” (Braithwaite et al. 2007, p.93) documentation practices meant that ARG members did not have a deep engagement with issues about dying and death of residents.
Indeed, as their reflections progressed, the group members’ discomfort with the talking to family caregivers about sensitive issues began to “leak out” through their stories. Complementing these insights were the critical dialogues with SCU staff that revealed a reluctance to talk about dying and death in the SCU. Research published after the completion of this study, in which Froggatt (2009) investigated ACP in UK nursing homes, supports earlier work (Caplan et al. 2006; Molloy et al. 2000; Phillips et al. 2006) that has highlighted inadequate staff knowledge, confidence and comfort around discussing sensitive issues. This can constrain the initiation of ACP discussions.

On the whole, the ARG members revealed that they felt ill-prepared to initiate conversations with family caregivers about ACP, suggesting this was the responsibility of GPs. In addition to their uncertainty about how to frame such discussions with family caregivers, they referred to the social unacceptability of discussing issues around dying and death. Similar issues have been highlighted in the literature (Komaromy 2000; Komaromy et al. 2000) such that death of residents in RACFs is a familiar but largely unacknowledged phenomenon, as it was in this study. The critical dialogues of the SCU staff members confirmed an absence of dialogue and supportive mechanisms (counselling, debriefing) that would foster more open acknowledgement of death in the SCU. Recent work (McDonnell et al. 2009) confirms that formal support for nursing and care staff after the death of a resident remains inadequate, which is consistent with earlier research (Ersek et al. 1999; Rutman & Parke 1992; Wilson & Daley 1998; Ersek & Wilson 2003).

The findings of this study support concerns raised by Ashby, Kellehear and Stoffell (2005, p.231) about the lack of acceptance of death within healthcare institutions and the need to re-examine “the place of death in the culture and processes” of settings such as aged care facilities. Within a “death defying” society (Abbey et al. 2006) where the imperative to “cure” shapes medical discourse, these dominant cultural imperatives have a profound impact on the practices of aged care staff. Indeed research conducted in the UK (Holman & Crowhurst 2009) found that care staff in a long-term care environment experienced a sense of failure when residents died. These staff shared a focus on “life sustaining rather than palliative care” (Holman & Crowhurst 2009, p.171). In this study, staff members’ taken-for-granted understandings about death and their collusion in sustaining silence about this familiar event, supports the dominance of a rehabilitative/restorative care culture.
(Jones, Cheek & Ballantyne 2002) that privileges economic rationalist interests (Angus & Nay, 2003). However, the implications of these unexamined ways of practicing were evident in the audit of files of residents (n=6) who had died in the previous 6 months in the SCU. The limited communication with family caregivers of a dying resident until the last week of life in addition to the absence of bereavement support for family members, while consistent with the literature (Shanley & Whitmore 2008; Clare & De Bellis 1997; De Bellis & Parker 1998; Maddocks et al. 1996), arguably represents a failure of managerial/institutional agendas to take account of “humanistic” needs.

It is perhaps not surprising that family caregivers (n=10), during their interviews, appeared to have little understanding about their role in decision-making processes for their relative’s care. As highlighted in the ARG reflections, some family caregivers’ deferral of their decision-making responsibilities to presumably more knowledgeable others (RACF staff and GPs) was an active decision by some not to be involved. It has been suggested that in part this is reflective of family caregivers who feel that they lack knowledge to make such decisions (Procter, Martin & Hewison 2002; Forbes et al. 2000; Caron et al. 2005b). Equally so, such a decision can be understood as a protective mechanism for some family, to distance themselves from potentially difficult and confronting conversations. In these circumstances, family caregivers may also be considered as unwitting collaborators supporting professional dominance over decision-making for the person with dementia. Indeed the “social death” and disability associated with dementia has been reported to deter family caregivers from talking about their relative’s condition (Shanley & Whitmore 2008, p.39). From these baseline findings it is clear that issues which influence open discussions and attitudes of staff and family caregivers towards death and dying are highly complex and culture bound. Nonetheless, through their critical reflections the ARG members came to understand that the alienation of family members from dialogues about dying and death was, as Freire (1970, p.26) might describe, “the result of an unjust order”. Reflective of the group members’ greater sense of ownership over this issue they planned to investigate how the existing structures and processes could be improved towards more “humanistic” ends. Thus, it was agreed that a review of the palliative care planning form would be undertaken to better reflect the needs of residents and their families, followed by a plan to explore possibilities for conducting palliative care case conferences with family caregivers of residents.
The final issue that the ARG members attended to in this first stage of the project was the perfunctory approaches to pain assessment and management. The limited use of systematic pain assessment tools, as revealed by findings of the audit, had been identified in the literature as an ongoing concern (McAuliffe et al. 2009; Radbruch et al. 2000; Neville et al. 2006) as well as problems with analgesic administration (Neville et al. 2006) and documentation of the outcomes of interventions to address symptoms (Ferrell et al., 1995). The audit findings are particularly disturbing because, as discussed in Chapter 2, pain is a commonly experienced symptom in people with advanced dementia (McCarthy et al. 1997; Parker et al. 2005; Lloyd-Williams 1996), and pain and symptom management is an integral component to the provision of a palliative approach (ADoHA 2006) to care.

Consistent with recent work by McConigley et al. (2008), the critical reflections of the ARG members highlighted excessive institutional/regulatory documentation requirements, heavy workloads and limited time that were tensions influencing their pain management strategies. Nurses in the ARG highlighted how they had become efficient at manipulating their documentation practices to reduce the burden on their already time-starved existence, while at the same time being able to claim RCS funding for the organisation. In this sense, the exercise of power by nursing staff to maintain habitual, ad hoc approaches to pain assessment and management reveals the operation of hegemonic power relations that support economic institutional interests. These findings resonate with Venturato et al.’s (2007, p.10) observations that nurses in aged care experience practice as “a form of minimalism”. This minimalist engagement (Venturato et al. 2007, p.10) is manifest in the findings of this study that suggest a failure of staff to take account of the complex and holistic pain related needs of residents. Having developed new insights into their habitual ways of managing residents’ pain and the disparity between these practices and evidence-based standards (APS 2005), the ARG members recognised an imperative to take action to reconfigure their practices in this area.

The group’s critical analysis of the data from Action Cycle 1 demonstrated a remarkable shift from their earlier reconnaissance discussions, wherein they had focused on seemingly irreconcilable interests that shaped their practices. These findings demonstrate the utility of critical action research in provoking previously isolated and disengaged aged care staff to constitute a “communicative space” (Kemmis 2001, p.103). When presented with an opportunity to share stories and
critically reflect on their practices the ARG members developed a deeper awareness of their taken-for-granted assumptions and the hegemonic interests that shaped their capacity to deliver a palliative approach to care. Having access to data from sub-cycles one to four and participating in the “construction and validation of meaning” (Lather 1991, pp.61,63) about emerging issues, opened up opportunities for the ARG members to see their once familiar situation “cast in a new light” (Rudolph et al. 2001, p.312). Consequently, group members shifted from a position of outward blame and powerlessness, to envisaging possibilities for strategic action to develop their practices around an evidence-based palliative approach to care.

To conclude this chapter, I return to the first research sub-question that was posed in Chapter 4: Is a palliative approach to care understood and reflected in the practices of aged care staff in the SCU?

The findings of the first stage of this study suggest that a palliative approach (ADoHA 2006) to care was minimally reflected in the practices of nursing and direct care staff in the SCU. Key issues that emerged from the multiple sources of data collected during Action Cycle 1 revealed a palliative approach to care was understood by most staff as equivalent to terminal care. In addition, pain and symptom management appeared inadequate and did not conform to best practice standards. There was an absence of ACP and a use of highly generic language in resident documentation that suggested staff members were ill-prepared to have conversations with family members about issues of dying, deterioration and palliative care. Despite death being a frequent event on the SCU there was an absence of open discussion about death and dying between staff members. The association between dementia and death was rarely raised with family caregivers and family involvement in decision-making was minimal. There was a lack of collaborative relationships between RACF staff and family members and fragmented relationships with GPs. Finally the findings of the study highlight that there was limited organisational infrastructure that would support the provision of a palliative approach. Rather, care provision maintained a dominant synergy with notions of rehabilitative/restorative care. As a consequence, palliative care operationalised as end stage or terminal care.
Stage 2: Emerging Empowerment

Stage 1 of this study exposed problems with SCU staff members’ knowledge of a palliative approach and suggested that ARG members were essentially disengaged from evidence-based practice. Moreover, problems with meeting the information and support needs of family caregivers and inadequacies in delivery of evidence-based resident care were apparent. The critical reflections of the ARG members on these issues revealed opportunities for change and challenged their previous assumptions of being powerless to construct their practices differently.

During Stage 2 the ARG members assumed a more proactive stance towards change. Herein, the ARG divided into two research sub-groups and conducted independent planning meetings, engaged in data collection and analysis activities to develop four evidence-based intervention proposals (Action Cycle 2). The intervention proposals were presented to the project steering committee for review and feedback (Action Cycle 3).

The collaborative engagement of the ARG members to systematically plan a number of intervention strategies demonstrated an emerging sense of empowerment. The group members’ participation in the research shifted from a “facilitated engagement” to them embracing roles as “practitioner researchers” (Dewing & Traynor 2005, p.701). This shift saw their continued commitment to reflecting on their practice and working towards change.
Chapter 7: Developing comprehensive intervention strategies

7.1 Action cycle 2

ARG members’ critical reflections on data from the first action led them to pursue four action areas. These being; i) staff knowledge and understanding about a palliative approach to care, ii) family caregiver information and support, iii) issues about palliative care planning, and iv) issues with pain assessment and management. Through their sustained engagement group members revealed a number of contradictions in how they described their palliative care practices and how in reality these were operationalised.

7.1.1 Plan

The group’s critical analysis of their situation emerged out of a highly collaborative, iterative process and in reality did not occur according to discrete stages of the action research spiral (Kemmis & Wilkinson 1998). Rather, as their interactions unfolded, the boundaries between the reflective phase of Action Cycle 1 and the replanning phase of the Action Cycle 2 were blurred. Therefore, while the group members had conceptualised action around four specific problems areas, they needed to develop strategic approaches for implementation. Mindful of the need for rigorous planning in action research (Street 1995; Kemmis & McTaggart 1988), Action Cycle 2 was approached with a deliberate intention to systematically develop comprehensive intervention strategies. During their planning activities, group members dialogically mapped data from their preliminary investigation (reconnaissance discussions and Action Cycle 1) that supported the need to take action across the four identified areas. I compiled a matrix of the ARG’s analysis that demonstrated how their planned actions emerged (see Appendix 15).
Planning activities unfolded between February and April 2007. This time frame was slightly longer than that originally anticipated, due to a number of extraneous factors. The group’s first two planning meetings were conducted with some success. However, they subsequently experienced an increasing number of interruptions by other staff at the facility. These interruptions were associated with staffing issues at the changeover of shift; visiting doctors requesting consultations with nursing staff in the ARG and interruptions by administrative staff. The high frequency of these distractions impacted on the ARG’s discussions causing them to become increasingly fragmented. During one meeting, when the group had been already interrupted three times, the frustration of some members was almost palpable after a fourth interruption. For example, Judy stated in exasperation, ‘I’ll be buggered, it never works does it?...it never works’. The ARG members were concerned that the numerous intrusions to their meetings were arresting their progress. In an attempt to remedy the situation they agreed to attend a three hour planning workshop, on their days off, at a location outside the facility, so that they could have an uninterrupted period of time to meet.

The planning workshop was conducted at the end of March and was crucial to building on the work of earlier meetings. During the workshop the ARG refined their plans of action and considered the realities of implementation, including potential barriers and pitfalls. Following the workshop, members met another three times. These meetings provided them with opportunities to finalise evaluation and monitoring strategies prior to taking action.
7.1.2 Take action and collect data

During the first 6 weeks (February to mid April 2007) of Action Cycle 2 group members located a range of resources and analysed these to plan their intervention strategies. The action planning workshop provided a forum for the ARG members to consolidate their efforts and decide on how they would both implement and monitor the proposed interventions. These activities are reported in detail below.

7.1.3 Knowledge and information needs of key stakeholders

7.1.3.1 Supporting staff members

The ARG’s preliminary investigation identified a number of issues related to staff members’ knowledge of a palliative approach; the best-practice Guidelines (ADoHA 2006) and communication about palliative care, death and dying on the SCU (See Appendix 15 - matrix of the ARG’s analysis). In an attempt to address these issues and support an educative agenda on the unit, the group members planned an intervention strategy focusing on the delivery of education sessions to staff members.

Firstly, with the reflections of the ARG in Action Cycle 1 having highlighted problems with a reliance on external sources of education and a lack of engagement with the evidence, group members discussed how they could assume responsibility for the development and delivery of the education sessions. Heather suggested that the education session contained in the Palliative Approach Resource Kit (which she received at Palliative Care Australia’s awareness-raising workshop) was an ideal evidence-based resource that could be used to facilitate staff education. Heather volunteered to facilitate the development and implementation of this intervention strategy, with the assistance of Anne. Subsequently, these two members met four times separately from the rest of the ARG to review Palliative Care Australia’s ‘Guidelines for a Palliative Approach in Residential Aged Care’ education session (PCA 2005a), make modifications and decide on how they would deliver it. At the action-planning workshop they reported on their progress. Anne explained that the education session addressed identified deficits in staff knowledge about the applicability and implementation of a palliative approach. At this point she provided the other ARG members with copies of the presentation for their feedback.

On reviewing the presentation, Judy suggested that the symptoms indicative of a terminal phase of life should be included, since findings from the palliative approach questionnaire demonstrated that the majority of SCU staff considered a palliative
approach to be the same as terminal care. She contended that discussing end-of-life symptoms would assist in addressing these knowledge deficits. Additionally, Elizabeth suggested that the presentation should make ‘explicit’ the contribution of PCAs given that data from the critical dialogues (Action Cycle 1) indicated that some PCAs did not consider palliative care as part of their role on the SCU. The final version of the presentation is contained within Appendix 16. Heather suggested that the proposed education program represented an important step towards opening a dialogue among staff about palliative care. To achieve this both Heather and Anne suggested conducting ‘interactive’ education sessions as a strategy to facilitate staff to ‘feel comfortable’ raising issues about palliative care.

When considering the risks of the action, the group members identified ‘staff resistance’ to the education sessions as a potential issue. Catherine asserted that staff may take the stance that ‘they already know’ about a palliative approach, even though data from Action Cycle 1 indicated otherwise. As the planning discussions progressed the ARG debated how the education sessions would be best delivered. Group members recognised that it may be difficult for SCU staff members to attend while they were on shift, due to the fluctuating care needs of residents and ongoing staff-shortage issues. It was agreed that staff would be encouraged to attend the sessions outside their shift hours. In response to this suggestion, Catherine joked that they would have to be ‘rounded up in a paddy wagon’ to attend if they were not reimbursed. In confirmation of this concern group members agreed that at the next project steering committee meeting they would request that facility management provide financial support for the intervention.

The group then went on to consider the issue of evaluation. They planned to ask staff to complete feedback forms because they considered this a ‘non-confronting’ method of eliciting staff perceptions. The group subsequently worked together to develop a staff feedback form in a similar style to other feedback forms used at the facility (see Appendix 17). Some questions used on the feedback form were based on items from the PAQ to which staff responses indicated deficits in understanding, including:

“For whom is a palliative approach to care appropriate?”

- “When should a palliative approach to care be implemented?”
- “Who can implement a palliative approach to care?”
The plan of action emerging from the group’s discussions was that Heather and Anne would deliver two interactive education sessions to SCU staff. They would be about a palliative approach to care and the Guidelines (ADoHA 2006) using a modified version of the Microsoft PowerPoint presentation from the Palliative Care Australia resource kit (PCA 2005a).

7.1.3.2 Knowledge and information needs of family caregivers

In addition to conducting education sessions for SCU staff, the ARG members were keen to address information needs of family caregivers about dementia, palliative care and the special care environment. Their reflections in Action Cycle 1 highlighted an absence of information resources in the SCU for family caregivers. In response to this, group members worked together to locate and review resources that could be used to address family caregivers’ information needs. The ARG’s data-collection activities included reviewing the Guidelines (ADoHA 2006), contacting other RACFs; and sourcing information from Alzheimer’s Australia and other information networks. Members met independently to review the various information resources they had located. From these deliberations they chose to use an information booklet titled “Information for family and friends of people with severe and end stage dementia” (Blue Mountains Division of General Practice (BMDGP) et al. 2006). Heather reported on their progress during the action planning workshop, stating that they considered the book to be an ‘excellent’ resource and explained ‘the beauty of this book is that it says [the symptoms are] normal!’: Anne suggested that it could allay some of the family caregivers’ ‘fear’ and ‘anxiety’ about some of the confronting symptoms of dementia. Permission to use the booklet was obtained from its authors and minor modifications were made to adapt it to the local context (see Appendix 18). Members agreed to include it in an information package given to family caregivers.

In the absence of finding any suitable resources that contained information about dementia-specific environments, Catherine and Elizabeth suggested that the ARG develop a fact sheet about the SCU, to complement the information booklet. This initiative was supported by ARG members given the family caregiver interviews in Action Cycle 1 (see p.93) and the reconnaissance findings highlighted a need to provide family caregivers with information about the special care environment. Because Catherine and Elizabeth had frequent contact with family members, they chose to meet independently to develop a draft version of the fact sheet. They
reported to the ARG at the action planning workshop, at which point Elizabeth emphasised that the fact sheet contained information relevant to the needs of family caregivers as identified through the family caregiver interview data and the reconnaissance discussions. She explained that it contained information about ‘what family might see as they come into the unit’ and argued that it was important to highlight the uniqueness of the SCU compared with other settings. On this basis the fact sheet contained specific information about the layout of the unit, dementia care practices, types of behaviours displayed by residents and requirements of the secure environment (see Appendix 19).

During the planning workshop, the group members decided that they would be primarily responsible for the distribution of the information packages to family caregivers. Anne argued: ‘it should be up to us [the ARG] to give it [the information package] out... rather than leaving it to someone else that doesn’t know what it’s [the intervention] about’. Further, given the ongoing staffing problems on the unit, they argued that the intervention had a greater chance of success if they were to implement it rather than relying on other staff to take on extra duties. Judy stated: ‘[it’s] a big, big concern at the moment to try and get anything implemented ... without any increased stress or workload to the staff’. The ARG members considered themselves better positioned to implement it and monitor the impact. This meant that group members were responsible for approaching family caregivers, introducing the project, distributing information sheets and obtaining their consent to participate.

During the planning discussions I raised issues regarding ethical concerns about the recruitment of family members for data collection. As part of these discussions a recruitment algorithm was developed in consultation with the ARG members. This tool contained a preamble that group members would use when inviting the family caregiver to participate in the intervention and provided a step by step reference for recruitment activities (see Appendix 20). During the development of the algorithm, the group members identified that information packages would be offered to family caregivers who were the nominated “contact person”8 in the resident’s file. Moreover, only relatives of residents who had been in the unit for longer than one month would be approached. Group members agreed that providing information to family caregivers any earlier than one month after admission would be problematic.

---

8 As demonstrated in the documentation audit conducted in action cycle 1, no residents had an enduring guardian (legally appointed decisionmaker). Therefore, consistent with facility policy the first nominated contact person in the resident’s file is considered the ‘person responsible’ with whom care processes are discussed and decisions made.
and may cause undue distress. In these discussions 28 family caregivers were identified as potential participants.

A modified version of the evaluation form, originally developed to accompany the information, was used (with permission of the authors) to evaluate the impact of the intervention. This evaluation contained items on an “agree”/“disagree”/“not sure scale” (see Appendix 21) as well as some short-answer items. In consultation with the group, a similar evaluation form was designed for the SCU fact sheet (see Appendix 22). Both evaluations sought feedback, about the usefulness of the information resources; whether family caregivers found the package confronting; and opinions about future use of the information package for the family caregivers of newly-admitted residents. Family caregivers would be asked to return the evaluation forms within 2 weeks of receiving the information package.

However, group members recognised that a potential risk to the action was if family caregivers did not return evaluation forms, thus jeopardising their ability to evaluate the impact of the intervention. To address this concern they agreed to seek permission from family caregivers to contact them with a follow-up phone call if they had not returned the evaluation forms within 2 weeks of receiving the information package. The recruitment algorithm (see Appendix 20), referred to above, prompted staff to seek this permission from family members and this same request was also outlined on the participant information sheet (see Appendix 23) and consent forms (see Appendix 24) that I assisted the ARG to develop. These documents were all given approval by the University Human Research Ethics Committee (HREC), University of Tasmania and group members planned to distribute them to the family caregivers consistent with ethical guidelines. In order to track family caregivers that had returned evaluations, each information package and corresponding evaluation forms would be marked with a unique code. This process (also given HREC approval) meant that family caregivers from whom evaluation forms had not been received were easily identifiable. ARG members also planned to keep supplementary field notes and meet one month after the commencement of the action to monitor its conduct and to report of their impressions of its effectiveness.

---

In summary, the action plan agreed among ARG members was to provide eligible family caregivers (either in person or via the phone) an opportunity to receive an information package that contained; (i) a booklet about dementia, (ii) a fact sheet about the SCU, and, (iii) evaluation forms. ARG members would track those people who returned evaluation forms and provide a follow-up reminder call to those family caregivers (with their consent) who had not returned the evaluations 2 weeks after receiving the package.

7.1.4 Reconfiguring care practices

In addition to identifying the information and knowledge-related needs of staff and family caregivers, data from the preliminary investigation revealed significant gaps between current care practices and best-practice standards. The ARG therefore developed intervention strategies in relation to pain management and palliative care planning. They considered these two issues central to supporting an evidence-based palliative approach to care.

7.1.4.4 Pain management practices

As outlined in Appendix 15, evidence from several data sources confirmed that staff practices in relation to pain management did not represent best practice standards. Therefore, group members planned to reconfigure their practices from a reliance on informal assessments, anecdotal reporting and subjective decision-making, to support the conduct of formalised pain assessments and more structured reporting mechanisms.

During their planning discussions the ARG members continued to interrogate issues around pain management in the SCU. Nursing staff in the group recounted how they relied on the proxy reports of PCAs to inform them about a resident’s pain status. Anne asserted: ‘realistically, they [care staff] know the residents more than what I do’. It was also apparent that while PCAs were often the first to recognise that a resident was in pain, their contributions were not always valued. Elizabeth recalled instances when she had reported to a nursing staff member that a resident was expressing signs of discomfort and was met with what she described as a ‘very negative response’, dismissive of her concerns. Anne acknowledged that PCAs on night duty had voiced similar concerns and went on to explain that the verbal transfer of information was not effective in ensuring good pain management for residents. However, as Judy critically reflected on this discussion she contested that the
Informal transfer of information was the sole cause of poor pain assessment. She revealed that after having been alerted to the possible presence of pain by a PCA, nursing staff ‘don’t implement the [assessment] tool’, suggesting that they did not prioritise systematic assessment processes. Heather confirmed this when she stated:

[A carer might say to nursing staff] ‘oh so and so when we move him ... first thing in the morning he has indicated to us that he had got pain’, so we’ll (nursing staff) just start something [analgesia]....

Reflecting on these narratives Anne asserted that there was an imperative to support PCAs to participate in pain assessment and management processes in a structured way. The group members supported this suggestion and agreed that such a process also needed to engage nursing staff to adopt more formal, evidence-based assessment and management procedures. In this endeavour, the ARG members accessed evidence to inform their planning activities, including the ‘Pain in Residential Aged Care Facilities – Management Strategies’ (APS 2005). Through these data collection processes and from extensive discussions, the ARG developed a collaborative Pain Assessment and Management (PAM) strategy. The strategy aimed to; (i) facilitate collaboration between PCAs and nursing staff, and (ii) engage staff members in undertaking formal pain assessment and management/review activities.

In terms of process, the strategy was based around PCAs being able to formally undertake pain assessments on residents and provide these assessments to a nursing staff member for review/confirmation and subsequent action. PCAs could conduct an assessment on a resident they suspected had pain using the existing pain assessment tool at the facility; the Abbey Pain Scale (Abbay et al. 2004). I worked with the group members to modify the structure of the assessment form so that there were spaces for PCAs to document their observations and for the RN or EN to review these and indicate their follow-up intervention. The modified form became known as the PAM form (see Appendix 25). It contained a series of instructions for use that aimed to ensure that clinical supervision, appropriate intervention and feedback by nursing staff was provided. During the development discussions, Judy had emphasised that in maintaining professional and legal requirements nursing staff would ‘confirm’ each PCA assessment and make a ‘judgement’ as to the appropriate pain management intervention. In this respect nursing staff remained responsible for the pain assessment and intervention, consistent with their scope of practice in the facility and legislative requirements of their role.
When considering the impact of the intervention, Anne postulated that implementing the PAM strategy would improve the ‘continuity’ of pain assessment and management for residents. Similarly, Catherine argued that the PAM form would facilitate pain related documentation that was ‘much clearer’ compared to the current processes. Additionally, group members hoped that the action would assist PCAs to feel more confident to approach nursing staff with documented evidence indicating a resident was in pain. As Heather explained, ‘a carer can say [to the RN/EN] “look I’ve assessed this person and they equate to this [Abbey pain score]”. She went on to postulate that with a more formal pain assessment process, nursing staff may be more diligent to act on the concerns of PCAs. In support of this rationale, Catherine asserted that processes that may enable PCAs to adopt a more proactive stance towards pain management ‘would be nothing but positive’ toward improving resident care.

During the planning workshop the ARG members considered the risks to executing the intervention successfully. These discussions occurred partly in response to a concern raised by Anne, that PCA staff might not participate in the intervention or complete the PAM form if they ‘didn’t feel comfortable’ to do so as part of their existing role. In acknowledgement of this concern, members decided that education about the PAM strategy and key aspects of pain management should be included in the education sessions about a palliative approach and the Guidelines (ADoHA 2006). This was considered to be a supportive space to introduce PCAs and nursing staff to the PAM strategy, where they could be encouraged to ask questions and share concerns. Moreover, members also recognised that the PAM strategy could be used in the education sessions as an example of how the practices of aged care staff could be reconfigured to better support a palliative approach to care.

Given that my recent work history was as a clinical nurse educator with a registered training organisation, I had access to education sessions about pain management in RACFs and provided these to the group members. I assisted the group to develop a brief presentation from these resources that covered the following topics:

- Principles of good pain management;
- Common barriers to good pain management, impact of poor pain management; and
- The PAM strategy.
A second risk identified by the ARG related to the manageability of the intervention. They recognised that the conduct of the action relied on the participation of other staff and that this carried risks of non-participation and also of overzealous participation, both of which would require future negotiation by members. In recognition of these concerns Heather suggested to ‘do a pilot’ with ‘four residents’ known to have ongoing problems with pain. Others members were supportive of this suggestion as it would enable them to monitor the progress of the intervention closely. To evaluate its impact the ARG members decided that they would conduct an audit of the PAM forms for quality and completeness of documentation, in addition to keeping field notes. These documentation sources would be analysed during ARG meetings while the intervention was being trialed and following its completion.

In summary, the group members planned to conduct an information session for SCU staff about the PAM strategy, in conjunction with the palliative approach education session. Following this, a pilot of the strategy would be conducted with four residents known to have problems with pain and those staff members that attended the education sessions would be encouraged to participate.

7.1.4.2 Palliative Care Planning

Lastly, the ARG members discussed the inadequacy of the current processes for palliative care planning in the SCU. As demonstrated in Appendix 15, data from the group’s preliminary investigation revealed that communication with family caregivers about palliative care planning was rarely initiated. There was also evidence to indicate a paucity of documentation in resident files detailing the wishes of family caregivers to guide end-of-life care.

Consistent with their reflections in Action Cycle 1 the ARG members agreed that the existing palliative care planning form used at the facility was inadequate. Judy reiterated that it needed to be ‘more specific and more detailed’, so that staff members would be more likely to elicit family caregivers’ wishes. As part of developing a revised form, the group members discussed what information may be important to capture. They posed key questions such as ‘is the resident for [resuscitation]… active treatment…hospital transfer… administration of antibiotics?’ During this process they also consulted the Guidelines (ADoHA 2006) to review specific evidence to ACP for people with advanced dementia and reviewed...
other online resources provided by Palliative Care Australia (PCA 2005c). To inform the development process we also located a range of planning documents used by other service providers that they could review. These included:

- ACP package from the local division of general practice – “statement of wishes document” (Southern Division of General Practice 2006).
- Plan of treatment document, advance care plan document and fact sheet from the Central Coast Division of General Practice (Central Coast Division of General Practice 2006).

The ARG members met independently of me to review the documents and a key outcome of their deliberations was that they planned to replace the existing palliative care planning form, used in the SCU, with a Plan of Treatment (POT) document (Central Coast Division of General Practice 2006). The group members worked to modify (with permission from the authors) this document. The revised POT (see Appendix 26) contained three levels of care, these being; “Palliative 1”, “Palliative 2/Limited”, “Active/Intensive”. The group members also collaborated to develop an information sheet for family members about relevant aspects of ACP, titling it “Advance Care Planning for People with Advanced Dementia” (see Appendix 27).

Given that the interview data in Action Cycle 1 indicated that family caregivers did not have a good understanding about the association between dementia and death or for that matter palliative care, members chose to use the term “advance care planning” because they considered that this may not be as confronting as using other terms such as “palliative” or “end-of-life” care planning.

Developing the POT was an extensive process for the group and comprised the major component of their planning activities for this intervention. While cursory ideas about how a process of case conferencing might be implemented in the SCU emerged during the groups deliberations, they decided to conclude their planning activities at this stage given the large amount of work that lay ahead of them in implementing the earlier three intervention strategies. The group members made a strategic decision to revisit this intervention later in the research process. Group members directed their focus and energies toward implementing the education sessions, distributing the information packages to family caregivers and implementing the PAM strategy.
7.1.5 Analysis and reflection

At the end of the action planning workshop and at a subsequent meeting the ARG members reflected on the large amount of work they had achieved in developing their intervention strategies. Their discussions indicated a growing recognition of the value of collaborating and sharing knowledge. For example, Anne emphasised that Elizabeth and Catherine had ‘done a really good job’ developing the fact sheet and highlighted the valuable local knowledge that these two staff members had contributed to the action. Catherine and Elizabeth also reflected positively on their experiences of collaboration to develop the SCU fact sheet and shared a renewed appreciation of the complexities of their job. For example, Elizabeth conceded that prior to the research she had rarely given consideration to the unique set of skills and knowledge she possessed. She stated: ‘you don’t really think about it, it’s your job’. Catherine agreed with this comment and added ‘it opened our eyes’, referring to their recognition of the expertise that they used on a daily basis while caring for residents and their family members on the SCU.

The reflections of other ARG members also suggested that their involvement in the project had challenged their previously taken-for-granted perceptions of their scope of practice. This was apparent when Anne raised concerns that staff may, as she described, ‘pounce’ on her when delivering the education sessions. Likewise, Heather indicated uncertainty about assuming a role that had previously been left up to other “experts”. Yet as they progressed through the planning activities they reported developing greater confidence in their ability, as was evident when Heather reported in her field notes ‘…I actually feel more confident about the presentation’.

I also reflected on ARG members’ engagement in this action cycle and recorded in my journal how developing the intervention strategies had been: ‘...an intense professional development activity for group members’ (Researcher Journal April 3, 2007). Having an opportunity to reflect on their planning activities when producing the case notes from the group meetings and the workshop later led me to write that the:

*Group members were provoked to conceptualise how they wanted their practices ... to be different in the future and this is something that they have not systematically done before in the inertia of everyday work.*
When I shared these sentiments with the group members in a later meeting, they reflected how, in the context of their day-to-day work, they did not have an opportunity to think about or explore their practice systematically. Judy emphasised the importance of having time away from everyday work demands to talk with colleagues about practice and collaborate to arrive at new understandings. She reflected, ‘when you have time to sit and think about it [your practice] there is so much positive stuff that comes out’.

The group was keen to present their new understandings of practice and intervention strategies to the project steering committee. It was important that the ARG seek feedback from these key stakeholders in order to validate their developing analyses of their situation and receive support for their intervention proposals. Thus, the group progressed to a third action cycle.

### 7.2 Action cycle 3: Feedback to key stakeholders

In this action cycle the steering committee were provided with a summary of the key research findings from the preliminary investigation, as well as the proposed intervention strategies. As described in Chapter 4, the Steering Committee’s terms of reference outlined a responsibility to monitor the research group’s activities and provide review and feedback on the research findings and intervention strategies. The committee was also charged with the responsibility of recommending resources and facilitating the ARG’s access to other information toward enhancing the planning and/or conduct of the proposed interventions.
7.2.1 Plan

As the ARG members discussed the data that would be provided to the steering committee they recognised that some of these findings and a number of their reflections about their work conditions and deficits in palliative care practices may be confronting. Nonetheless, the consensus amongst the members was that the committee should have access to their critiques and experiences. Anne stated ‘I think it’s important that they know [about staff, resident and family members experiences and practices], otherwise they are not getting the full story!’

Hard copy versions of resources developed for use in the intervention strategies (i.e. the Information Booklet, SCU Fact Sheet, PAM form and POT) would be provided for the steering committee to review. It was agreed that in addition to myself, Heather would represent the ARG at the meeting and we would report back to the group.

Figure 17  Action cycle 3 - Action plan

Concern:
Seek feedback and support from key stakeholders.

Action plan:
Present account of key issues and intervention strategies (via PowerPoint presentation) to the steering committee, seek their feedback and report back to the ARG on outcome of the meeting.

Monitoring:
• Heather to attend steering committee meeting
• Researcher to keep notes pertaining to discussions
• ARG meeting – post steering committee meeting

Data sources:
Research group case notes
Researcher’s notes from meeting and journal account

Analysis:
Collaborative analysis of researcher’s notes from meeting and journal account
Collaborative analysis of ARG case notes

7.2.2 Take action and collect data

Four of the 10 steering committee members were unable to attend the meeting, despite extensive efforts to arrange a suitable time. These members included a representative from the Department of Health and Ageing, the GP, consumer representative and an allied health staff member. Information was made available to these members, with an opportunity to provide feedback. Those who did attend
included the palliative care consultant, a member of facility management, the Professor of Aged Care Nursing and the dementia nurse specialist. Despite the incomplete attendance at the meeting I noted in my journal that the findings of the first action cycle were generally well received by the committee and members gave ‘constructive and positive feedback’.

On reviewing the data from Action Cycle 1 that highlighted the lack of staff education in relation to the Guidelines, the member of facility management acknowledged that ‘probably not enough had been done’ to raise the awareness of staff members in this area. However, at the same time she also emphasised that the delivery of such education was the responsibility of the two senior staff members who attended the awareness-raising workshop for the Guidelines (ADoHA 2006). It was at this point that Heather, who attended the workshop, contested the manager’s critique and voiced her experiences of the significant barriers to setting up and undertaking education sessions. She explained that while being aware of her responsibility to deliver education and raise staff awareness about the Guidelines (ADoHA 2006), the effects of heavy workloads, staffing shortages and regulatory requirements undermined her ability to fulfil this role. I recorded in my field notes that steering committee members ‘acknowledged these circumstances as legitimate barriers to education at the RACF’ (Researcher Journal April 2007). Thus, the committee affirmed the ARG’s proposal to deliver targeted, accessible education sessions addressing the Guidelines and key aspects of a palliative approach. Acknowledging the veracity of the group’s critique, the member of facility management referred to the education sessions as ‘important professional development’ for staff and agreed to the group’s request that the facility pay staff to attend the sessions.

When data about the information needs from family caregivers were presented to the committee, a number of members readily identified with this issue. For example, the dementia nurse specialist confirmed the legitimacy of the issue when she reflected on how family caregivers in aged care environments ‘struggled to make sense’ of their relative’s dementia. In response to such concerns the member of the facility management highlighted that previously ‘support…sessions [and]…afternoon teas’ had been available for family caregivers at the facility, so they could meet and listen to invited speakers about dementia. However, she explained that these activities were not ‘particularly successful’ as attendance was poor and often the events had to be
cancelled. After being presented with narrative accounts of family caregivers that revealed their desire for greater staff engagement and information sharing, the management staff member surmised that the provision of information packages to family caregivers would be a ‘non-intrusive’ method of delivering sensitive information. However, the committee member also expressed concerns about PCAs in the research group providing information to family caregivers. She queried whether this activity was outside their professional ability. Given that this concern had been subject to discussion amongst the ARG when developing the plan of action, Heather responded that the participation of PCAs would not exceed what would be considered as “normal” practice and they would be supported and indirectly supervised in these activities by the nursing staff (RN/EN) in the group.

Following on from the above discussion, an account of the issues underpinning the development of the pain assessment and management strategy and the palliative care planning intervention were presented to the committee. The majority of the committee discussions focused on the findings of the documentation audit that revealed how resident documentation was to varying degrees repetitive, not individualised and incomplete. Committee members were supportive of the ARG’s critique of how regulatory conditions impacted on their documentation practices. The facility manager acknowledged that documentation was often completed with a focus on quantity to satisfy the requirements of the Aged Care Standards and Accreditation Agency; with adverse effects on quality. It was apparent that this issue held particular resonance with the member of facility management, as she emphasised that most staff ‘do the best that they can’ to negotiate competing demands of workloads, short staffing and documentation requirements. However, she argued that aged care staff (including those in her position) were largely powerless to change these circumstances given the regulatory requirements directly linked resident documentation and federal resource allocation. The manager’s implication of being “at the hands” of bureaucratic structures echoed the concerns of the research group.

With the material and political constraints on the practice of staff members having been the subject of considerable discussion, the palliative care planning intervention received a somewhat cautious response. It was described by one of the committee members as an ‘ambitious plan’ given the complexities of organising case conferences in a resource-stretched environment. However, the goal of the strategy was well supported by the committee members. For example, the dementia nurse
specialist emphasised that from her experience the implementation of a formal planning process, in a timely and sensitive manner, could help to avoid what she described as ‘default reactions’ by either staff or family caregivers that often resulted in inappropriate treatment decisions such as hospital transfers. While in support of the proposal, the palliative care consultant also suggested that the research group seek ‘legal advice’ to ensure that the POT form contained legally appropriate statements and preamble. Committee members agreed that the Public Guardian was the appropriate professional to consult. Additionally, the palliative care consultant highlighted the ‘synergy’ of the group’s proposal to a “Respecting Patient Choices Program” (2007) already running at a regional public hospital. The consultant suggested that the group explore options for accessing resources from this program to assist them in future planning of the intervention.

The PAM intervention was the final topic for discussion and it received a supportive response from the committee. The dementia nurse specialist highlighted pain management as a ‘common challenge’ she encountered when visiting aged care facilities and she asserted that the implementation of evidence-based strategies across the aged care industry was an ongoing concern. Committee members suggested minor amendments to the layout of the PAM form and in addition, the member of the facility management requested that a document outlining the PAM strategy be produced as a guide for staff outside the ARG who would be involved in the intervention. Overall, the steering committee members provided their support for the group’s proposals for action with the following recommendations:

- **Staff education intervention**: That the facility pays staff members to attend education sessions as a professional development activity.
- **Pain Management Intervention**: Incorporate suggested amendments to the PAM form and develop a summary of PAM protocol as a reference for staff in the SCU.
- **Palliative Care Planning Intervention**: Investigate possibility of obtaining support from the RPCP and seek legal advice on the POT document.

### 7.2.3 Analysis and reflection

Following the steering committee meeting, Heather and I reported to the research group. Their discussions comprised the analysis and reflection phase of this action cycle. Group members were encouraged by feedback from the steering committee.
They were ‘especially impressed’ that a member of the facility management had agreed to pay staff to attend the education sessions. This gesture of material support represented to the group that their analyses and suggestions were considered legitimate points of view and in their words ‘accepted as important’. The group’s reflections at this stage were only brief as they were keen to progress to the next action cycle, to further refine their intervention strategies in line with the committee’s recommendations and take action.

7.3 Discussion

The findings from this stage of the study highlighted the ARG members’ emerging sense of empowerment as they assumed an increased commitment to and authority over the direction of the research. This shift was evident as group members planned and took action to develop comprehensive intervention strategies around four areas of practice. Consistent with the theoretical foundations of critical action research, “concrete” and “particular” practices (Kemmis & Wilkinson 1998, p.24) arising from complex socio-cultural and material conditions were the foci of the group’s action. By drawing on critical insights they had developed during their preliminary investigation, in addition to locating and reviewing a range of evidence-based resources, the group members demonstrated what Friedman (2001, p.132) has referred to as “research in practice” as opposed to “research on practice”. In keeping with this perspective the group members were more than just “problem solvers”, (Friedman 2001, p.133) they were becoming researchers intent on critically examining their reality in order to transform it (Fals Borda 2001). Adopting the role of “practitioner researchers” (Dewing & Traynor 2005, p.701), the ARG members challenged the inevitability of their circumstances and proactively investigated ways that their practices could be transformed. Having developed a number of action plans, the group’s decision to delay further planning around palliative care case conferencing was reflective of their developing capabilities as researchers, concerned with the successful implementation of action.

The value of meeting together over a sustained period of time was evident in reflections during this stage of the study. Their collaborative reciprocal dialogues during Action Cycle 2 indicated an emerging belief that change was in fact a possibility. Underpinning this realisation was the group members’ new appreciation of their capabilities as nurses and carers emerging from a rich background of experience in aged care. For example, the recognition for Catherine and Elizabeth of
their previously taken-for-granted skills and knowledge about providing care for people with dementia emerged through their collaboration when developing the SCU Fact Sheet. Similarly, it was evident that Heather and Anne’s confidence about implementing education sessions markedly increased as they engaged in the process of developing the education and seeking feedback from the other ARG members. By engaging in activities to proactively locate/review evidence, develop resources, plan action and strategies for implementation, the group members could be understood as having “expanded the boundaries” (Gaventa & Cornwell 2001) of their practice. By sharing in the process of knowledge development people could shift the boundaries of what they conceived to be possible. Indeed with a growing awareness of themselves as “active” (Heron & Reason 2001, p.144) participants capable of interrogating their own knowledge and participating in the production of new knowledge, the group members challenged their previously taken-for-granted position as passive recipients of information. These findings set this study apart from the literature that has reported PCAs as having little recognition of, or access to, best practice evidence (Janes et al. 2008) and nursing staff as struggling to actively engage with evidence-based practice (Spear 2006).

The emerging empowerment of group members during Action Cycle 2 marked a shift from what Robinson (2001, p.118) has termed a “researcher-facilitated process” to one that resembled the “negotiation of power”. This shift was evident in the group’s plans to take strategic action that would challenge hegemonic power relations and was suggestive of what Lather (Fox cited in Lather 1991, p.4) referred to as “people coming into a sense of their own power”. Reflective of this changing dynamic, was the group’s decision to include within the presentation to the steering committee some of the more confronting aspects of their analyses. This decision reflected the exercise of power by the group to raise awareness about how at the micro-level of practice, regulatory structures and dominant institutional interests constrained the ability of staff to support an evidence-based palliative approach to care. Sharing their critiques with the steering committee was illustrative of how their critical collaborative, engagement had become a driving force to, as Comstock (1982, p.386) explained, “inform and initiate politically-informed action”. Furthermore, during the steering committee meeting Heather’s contestation of some perspectives put forward by a facility manager was illustrative of what Bishop (2008, p.1674) described as people developing a “sense of themselves as having an
authoritative voice”. Here Heather’s resistance was suggestive of a sense of personal empowerment emerging from what was collaborative effort.

Overall, the support and feedback from the members of the steering committee was important to the continued confidence of the group members and the progress of the project. These professionals, by virtue of their positions, were considered as “experts” by the ARG and thus the committees’ acknowledgment of the veracity of group’s critique suggested that “legitimate” concerns from practice had been raised. The support of the steering committee reinforced group members’ sense of confidence in their roles as “co-researchers” (Heron & Reason 2001, p.144). The agreement of facility management to pay staff members to attend the proposed education sessions was particularly important because it demonstrated an expression of material support for the project, despite the reports of ARG members about ongoing resource shortages. Moreover, the committee’s recommendations about how to improve the likely success of the intervention proposals also opened up opportunities for the group members to access other information networks (e.g. the Respecting Patient Choices Program (2007), the Public Guardian). This finding highlights what Foucault (1977b) has detailed as the “productive” (p.119) and “positive” (p.121) features of power that in the context of this project was exercised through the network of relations in the steering committee.

The findings of this stage of the study have demonstrated how critical action research can provide opportunities for information sharing across hierarchical relations to facilitate the development of staff practices to support the delivery of a palliative approach to care. The affirmation of intervention proposals, with some minor amendments, inspired the group members to maintain their momentum and move on to the next stage.
Stage 3: Reconfiguring Practices: Engaging in The Politics of Change

This final stage of the study involved the implementation of the ARG’s planned intervention strategies. Reflective of the members’ increased autonomy in the research process, they were responsible for the conduct of the following action cycles.

- SCU staff education sessions (Action Cycle 4);
- Provision of information packages to family caregivers (Action Cycle 5);
- Pilot of PAM strategy (Action Cycle 6);
- Networking with experts to support the development of a palliative care planning intervention (Action Cycle 8);
- Pilot palliative care planning intervention (Action Cycle 9).

While I did not directly participate in action cycles, I continued to meet with the group on the completion of each action cycle, which provided me and them with opportunities to review their progress. The findings of this stage chart the group’s engagement in the politics of change and their “struggles” (Kemmis & McTaggart 1988, p.12) towards improvement within an environment characterised by complex socio-political, cultural and material conditions. The “essentially risky” (Kemmis & McTaggart 1988, p.12) nature of action is evident in this chapter as is the abiding commitment of the ARG members to seek new ways of working until their participation was no longer sustainable.
Chapter 8: Taking action to support evidence-based practice: part I

By stage three of the study, ARG members had progressed through three action cycles and planned intervention strategies aimed at improving four areas of practice. Action Cycles 4 and 5, reported in this chapter, were implemented sequentially and focused on improving staff members’ knowledge about a palliative approach and addressing the information and support needs of family caregivers, respectively.

8.1 Action cycle 4: staff education sessions

Figure 18   Action Cycle 4

The intervention strategy developed by the ARG to deliver education sessions for SCU staff about a palliative approach and the Guidelines (ADoHA 2006) is outlined in Figure 19. It involved the delivery of two education sessions by members of the ARG.
### Action Cycle 4 - Action plan

**Problem:** Insufficient staff knowledge of a palliative approach and the *Guidelines.*

**Constitutive Concerns:**
- Knowledge deficits regarding a palliative approach to care. [Action Cycle 1: Findings of PAQ]
- Absence of open discussion amongst staff about issues associated with palliative care, death and dying. [Reconnaissance: ARG discussions; Action Cycle 1: Critical dialogues with staff]
- Problems accessing education about palliative care, and education sessions held by external providers often lacking in relevance [Action Cycle 1: ARG Collaborative Analysis]
- No previous education for SCU staff, focusing on a palliative approach to care in the aged care context or on the *Guidelines* (ADoHA 2006) [Action Cycle 1: ARG narratives]

**Strategy for Action:**
- ARG members (Heather and Anne) deliver two education sessions to SCU staff, using the Palliative Care Australia, Palliative Approach resource kit.
- Anne will also introduce SCU staff to the intended pilot of the PAM strategy.

**Monitoring:**
- Record ARG members meetings
- ARG members to keep field notes/journal.
- Staff feedback forms
- Researcher to keep journal/field notes.

**Data sources:**
- Research meeting case notes
- Staff feedback forms
- Researcher’s journal and field notes

**Analysis:**
- Collaborative thematic analysis of ARG meeting data.
- Qualitative analysis of staff feedback forms, ARG members’ field notes and researcher’s field notes.

#### 8.1.1 Planning action

Action Cycle 4 commenced with the group members organising the times and dates for the conduct of the staff education sessions. The sessions were planned to occur 2 weeks apart between 1.30 and 2.30pm, which was the shift cross over time. These times were chosen so that staff working an afternoon shift could come in prior to their shift to participate. Depending on the circumstances on the SCU, the ARG members reasoned that one or two staff members from a morning shift would also be able to attend. The times and dates were approved by the Facility Manager.

To inform SCU staff members about the education sessions, research newsletters (see Appendix 28) were developed and distributed to staff members with their pay slips approximately 3 weeks prior to the first session. In final preparation, Anne and Heather conducted a practice education session, whereby they delivered the...
presentation to ARG members as their audience a week prior to the first session. With neither Anne or Heather having previously been responsible for delivering education, having a ‘dry run’, as Heather called it, helped to build their confidence.

8.1.2 Take action and collect data

The two education sessions were held in May 2007. At the beginning of each session I introduced the speakers and explained that the education was part of the project. I distributed research staff feedback forms (see Appendix 17) and at this time indicated that I would be making notes throughout the session for the purposes of data collection and assured participants that any all data collected would be anonymous and confidential. Participants were given the option to decline participating in the action if they so desired. None of the participants withdrew.

Heather delivered the presentation about a palliative approach in an interactive manner to support the collaborative intent of the session. The presentation covered:

- The rationale for delivering a palliative approach to care;
- Development of the Guidelines;
- Summary of topics covered in the Guidelines;
- A palliative approach and accreditation: relevant standards;
- Three forms of palliative care – end-of-life care and symptoms indicating the terminal phase; specialist palliative care; and a palliative approach;
- Implementation of a palliative approach: Consideration of Guidelines One to Four;
- The role of PCAs in a palliative approach; and
- Group discussion around key aspects of a palliative approach and its benefits.

In order to contextualise the information presented, Heather drew on examples from the residents who staff cared for and invited group members to share their thoughts.

Following on from Heather and prior to introducing the PAM strategy, Anne provided a brief review of:

- Principles of good pain management;
- Common barriers to good pain management;
- Impact of poor pain management; and
- Pain signs and non-verbal indicators.
She then discussed the PAM strategy, and covered the following:

- Aims and rationale;
- Potential outcomes; and
- Example of the PAM form using a case study.

During the session Anne referred to the intervention strategy as an example of how evidence contained within the Guidelines (ADoHA 2006) could be implemented in practice, to provide continuity between her and Heather’s session.

8.1.2.1 Changing Understandings

I kept field notes about the sessions in my journal to enable me to reflect on the changes that I observed during the action. For example, I wrote:

> While we had hoped for better attendance; those staff that did attend were engaged and interested in the information being presented to them. Initially some staff members queried the legitimacy of a palliative approach as something different to the care that they currently provided to residents. One staff member stated: “I was of the understanding that staff already used this approach [palliative approach]”. However, as the education sessions progressed, these sceptical responses disappeared and most staff readily embraced opportunities to talk about their experiences of providing palliative care to residents and how a palliative approach would benefit residents in their care... I was somewhat surprised by the enthusiasm of the staff members to engage in discussions (Researcher Journal May 9, 2007).

Heather asked participants a number of questions at the end of the education sessions about how they understood a palliative approach to care, who would be qualified to deliver a palliative approach, and how it could be implemented. I documented in my field notes the dialogues between participants in the sessions. These interactions indicated that staff members understood that a palliative approach was provided to people based on need, rather than prognosis or diagnosis. For example, one participant stated ‘[a palliative approach is] for all residents on the unit’ (RN) while another added, ‘it can be offered to any resident in our facility suffering from any illness, dementia .... Discomfort... ’ (PCA). The participants also emphasised that a palliative approach encompassed more than end-of-life care, for example, one participant stated, ‘... it’s not restricted to...just before dying’ (RN). Other
participants held similar sentiments evident in statements such as ‘[a palliative approach] should be happening from the beginning of admittance [to the facility]’ (ECA); ‘it begins when older people enter the nursing home’ (ECA). Understandings about a palliative approach not being confined to specialist practice were also apparent, for example one participant stated: ‘A palliative approach is part of the philosophy of quality aged care...’ (RN), another participant commented ‘staff don’t have to be [specially] qualified... all staff can develop an understanding of the basic concepts of palliative care... ’ (ECA).

8.1.2.2 Initial Clues about the politics of pain management processes

No formal feedback was sought from participants on the information Anne presented about the PAM strategy. However, I noted a sense of disaffection amongst PCAs in the education session when their role in pain management was discussed. The journal entry of mine refers to one of the education session where all participants were PCAs:

Anne spoke to the staff about piloting the PAM strategy and introduced them to the PAM form. Through out the session she emphasised that the pilot aimed at improving pain assessment and management on the unit by formally recognising the contribution of care staff to this process. At the completion of the session Anne asked participants for their thoughts about the planned pilot. At this point one of the participants who was a PCA, referred to the PAM form as ‘a weapon’, asserting that it could be used to compel the RN or EN in charge of the shift to act on PCAs' concerns about residents’ pain. Other staff in the session agreed, sharing experiences in which their concerns had not been acted upon by nursing staff.

8.1.3 Analysis and reflection

8.1.3.1 Attendance and Staff Feedback

Eighteen out of a possible 42 staff members registered their interest prior to the education sessions. A total of 12 staff attended (6 staff per session), accounting for almost 30% of all SCU staff. With one exception (a RN), all attendees were PCAs and 5 were employed as permanent night staff. All of the participants completed and returned feedback forms to a secure drop box at the end of the sessions. Staff responses to items on the feedback forms are shown in Table 20.
Table 20  
Staff responses to items on education session feedback form  
(n=12)

<table>
<thead>
<tr>
<th>Questions</th>
<th>AGREE</th>
<th>DISAGREE</th>
<th>NOT SURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found it helpful to learn about a palliative approach.</td>
<td>84% (10)</td>
<td>8% (1)</td>
<td>8% (1)</td>
</tr>
<tr>
<td>Having a better understanding of a palliative approach will assist me in caring for people with dementia</td>
<td>92% (11)</td>
<td>-</td>
<td>8% (1)</td>
</tr>
<tr>
<td>The education session was easy for me to understand.</td>
<td>92% (11)</td>
<td>-</td>
<td>8% (1)</td>
</tr>
<tr>
<td>I am aware that a set of guidelines exist for a palliative approach in residential aged care</td>
<td>92% (11)</td>
<td>8% (1)</td>
<td>-</td>
</tr>
<tr>
<td>I know how to access the guidelines for a palliative approach in aged care, on the unit where I work.</td>
<td>84% (10)</td>
<td>8% (1)</td>
<td>8% (1)</td>
</tr>
<tr>
<td>The presenters were knowledgeable about a palliative approach.</td>
<td>92% (11)</td>
<td>8% (1)</td>
<td>-</td>
</tr>
<tr>
<td>I would like to attend more education about a palliative approach</td>
<td>84% (10)</td>
<td>8% (1)</td>
<td>8% (1)</td>
</tr>
</tbody>
</table>

Participants indicated via short answer responses what they considered to be the most useful part of the education session. These responses could be categorised broadly according to two common themes. Firstly, participants indicated that they valued having learned that palliative care encompassed a more holistic focus than end-of-life care. Comments included: ‘that palliative care involves more than just the dying process’; ‘understanding that palliative care is not just the last stage of dying’ and ‘understanding that palliative care starts as soon as they [the resident] enter the complex.’ Other participants comments suggested that they valued the opportunity to access new information, such as ‘knowing about the Guidelines’, as well as ‘learning about new practices’ and ‘interventions’ that staff members could implement to improve care provision. Participants did not indicate any parts of the education session that they considered to be least useful to them, nor did they indicate areas for improvement. However, one staff member did request ‘continuing education’.

Following the education sessions, group members met and reflected on their efforts organising and conducting the education sessions, as well as their perceptions of the impact of the intervention.

8.1.3.2  Staff Attendance: Reflections on the availability

With 30% of staff members from the SCU having attended the education sessions, the issue of attendance was the focus of some discussion. Group members
acknowledged that despite their best efforts to schedule sessions that were accessible to most staff and distributing newsletters, it was still not feasible for all to attend. Staff members who were rostered to work when the education sessions were scheduled found it ‘almost impossible’ to leave the unit to attend. For example, Anne reported that the unit’s leisure and lifestyle officer ‘couldn’t get backfill, so she couldn’t leave the unit to come [to the education]’. Through their deliberations group members accounted for the difference in the numbers of staff that registered to attend the education sessions (17) and those that actually attended (12) as a consequence of high resident care demands and fluctuating staff availability.

8.1.3.3 Perceptions of staff malaise

In addition to the issues of availability, ARG members contended that a proportion of staff on the SCU were ‘just not interested’ in engaging in professional development activities. Despite being reimbursed for their time, Anne highlighted what she considered to be a general apathy among staff members when she stated: ‘... I just found over the last 12 months... staff... who aren’t involved in [the research] are uninterested, uninterested in doing any extra’. Heather supported this perspective when she referred to PCAs on night duty, suggesting that ‘only a couple of them are really interested’ in developing their care practices and that ‘the majority of them just aren’t’. However, group members recognised the situation was not improved by them working on an opposite shift rotation to most of those staff who were absent from the education sessions. These circumstances meant members did not have an opportunity to discuss the education sessions with those staff or encourage them to attend. They considered whether the attendance rate reflected a lack of knowledge among their colleagues about the education sessions. There was agreement amongst the group members, that generally staff considered the education sessions ‘of interest’ to them Anne argued that from her perspective the awareness strategies had successfully ‘planted the seed’ of interest amongst staff. She recalled one staff, after having received the newsletter enthusiastically informed her “this is what I have been waiting for!”. Judy also claimed that the presence of the memos on the staff noticeboard did not go unnoticed and with 18 staff members having registered to attend she maintained that information dissemination was not a major concern.

As the group members continued to reflect, they also acknowledged management at the facility having been supportive of the education by agreeing to pay staff for their attendance. While group members considered this a positive gesture, they also raised
concerns about the implications of management not being explicitly involved in promoting attendance. Judy argued that staff had ‘heard nothing’ from the facility management about the education sessions. She claimed that in the absence of management actively promoting the sessions, staff were less likely to regard their attendance as important. Elizabeth agreed and reported that as a result some PCAs from the SCU had chosen not to attend the sessions. My experiences of working at the facility also supported these reflections.

8.1.3.4 Toward changing staff members understandings

Despite the problems encountered with attendance Heather asserted that education sessions had ‘raised the awareness’ of staff members about the palliative approach. Anne agreed and reflected that one of the most apparent impacts from the intervention was participants’ recognition of the applicability of a palliative approach in the SCU. Data from the evaluation forms supported her opinion, with 92% of participants ‘agreeing’ that having a better understanding of a palliative approach would assist them to care for people with dementia. The group members reflected that the education sessions had ‘opened up’ opportunities for promoting discussion between staff as to how they might able to better meet the needs of residents under the rubric of a palliative approach. Heather stated that using case studies to relate information under discussion to the care of residents had created an atmosphere of ‘mutual learning’ and what she described as a perception of ‘learning together’. The success in engaging staff through an interactive education style also highlighted the importance of providing opportunities for staff to talk away from the distractions of daily practice.

Having reflected on the evaluation data, group members were of the view that they had achieved an important step towards the implementation of a palliative approach on the SCU. Catherine reflected on the importance of enhancing staff members’ knowledge about a palliative approach when she stated: ‘I just believe that it’s [staff education] so important...because [Residents] can’t speak for themselves’. Catherine was overcome by emotion after having made this statement, which Heather confirmed to be ‘exactly right’. Such comments reveal how, through their critical reflections group members had developed a heightened awareness of the moral dimension inherent in their taking action.
8.1.3.5 Developing insights into unit politics

Despite having not collected formal evaluation data on the section of the education session that addressed pain management and the introduction of the PAM strategy, the reflections of the group members suggested the presence of political undercurrents between them and nursing staff on the unit. Heather reflected on some participants’ (PCAs) perceptions about the PAM strategy, as a ‘weapon’ to provoke nursing staff to act on the concerns of PCAs. She suggested that these comments exposed a ‘them and us’ mentality that existed in the SCU. This finding however, did not come as a surprise to group members as they had previously acknowledged the tensions between some PCAs and RNs/ENs around pain management (see p.198). Catherine asserted that this type of response from PCAs suggested an underlying sense of frustration associated with their concerns about residents’ pain having previously been ‘ignored’. For Heather, it was remarkable that PCAs who did not necessarily work together and had no previous experience of reflecting on their practice had mutually raised this concern. Indeed this ‘discovery’, as Heather described it, served as a powerful indicator of the need for change toward more collaborative care practices in the SCU.

8.1.3.6 ARG members’ growing recognition of their own competence

In their final analysis of the intervention, group members reflected on the connection between participating in the research and taking on the responsibility of addressing staff members’ knowledge deficits. Anne reported that she ‘most likely would not’ have undertaken the task of providing staff education, had she not been involved in the project. Judy highlighted that, in the process of group members undertaking the intervention, she had been provoked to reassess her own competencies. She explained that a GP who was visiting the unit had noticed the staff memo about the education sessions. To her surprise the GP announced that it was a ‘good idea’ for staff from the SCU to be providing the education, asserting ‘you are the specialists in the care of these people’ (residents). Reflecting on her astonishment at this comment Judy explained that she had never before considered herself to possess specialist knowledge, despite having worked in her current position for more than 10 years.
8.2 Action cycle 5: addressing information needs of family caregivers

Having successfully delivered the staff education sessions, the ARG members had a new sense of confidence and were enthusiastic to tackle the next intervention strategy. Here, Action Cycle 5 (see Figure 20) was concerned with addressing the information and support needs of family caregivers. Data generated during Action Cycle 1 highlighted the imperative to distribute information to family caregivers about dementia and the special care environment. During Action Cycle 2 the group members developed an information package and an intervention strategy to disseminate these to family caregivers. The action plan is summarised in Figure 21.
Figure 21  Action Cycle 5 - Action plan

Problem:
Unmet information and support needs of family caregivers.

Constitutive Concerns:
• Concerns that family caregivers’ have poor understandings about the dementia trajectory, the special care environment and specialized dementia care practices. [Reconnaissance: ARG discussions]
• Knowledge deficits of family caregivers in relation to biomedical aspects of dementia, dementia trajectory, how to access information. [Action Cycle1: Narrative accounts of family members]

Strategy for Action:
• Distribute information packages to family caregivers who agree to participate and keep a record of those family caregivers who have received the packages and returned evaluation forms.
• ARG members to provide all family caregivers (either in person or via phone) with an opportunity to participate in the intervention, in accordance with recruitment algorithm (see Appendix 20)

Monitoring:
• ARG members to keep field notes/journal.
• Record ARG meetings during the action.
• Researcher to keep journal/field notes.

Data sources:
• ARG meeting case notes
• ARG members field notes
• Family caregiver evaluation forms
• Researcher’s journal and field notes

Analysis:
Collaborative thematic analysis of ARG meeting data with research group.
Quantitative and qualitative analysis of evaluation forms
Qualitative analysis of ARG field notes and researcher’s field notes.

8.2.1  Take action and collect data

With the steering committee having sanctioned the ARG’s proposal to provide information packages to family caregivers, the intervention occurred across a one month period from May to June 2007. ARG members were responsible for recruiting family caregivers. Consistent with the strategy outlined in the ethics algorithm (Appendix 20) they approached all family caregivers who visited the unit during their shifts and invited them to participate in the intervention. Those family caregivers who did not regularly visit the SCU were contacted via telephone by a member of the group and offered an opportunity to receive a posted information package. Family caregivers who were interested in participating were provided with a participant information sheet (see Appendix 23) and consent form (see Appendix 24). They could then return a signed consent form in person or by post. After having
received this consent, an information package was provided to the signatory. Each information package was assigned a unique code (which appeared on the evaluation forms), that in turn corresponded to the name of the family caregiver who received the package. This enabled ARG members to track the return of feedback forms and provide a reminder call to family members 2 weeks following the distribution of the package if no evaluation had been returned. All information packages distributed to family caregivers contained a reply-paid self-addressed envelope, so that evaluation forms could be returned.

8.2.1.1 Monitoring: Early Success

Group members informally discussed the conduct of the intervention with each other at staff handover and decided to meet only if they encountered problems. With activities having gone to plan, the group did not formally reconvene until after the intervention was completed. During this time I remained in contact with them and kept field notes of these encounters.

Given the somewhat confronting nature of the family interview data the comments of group members suggested that they were relieved to find that family caregivers responded ‘positively’ to their approaches. On the day the intervention commenced Anne successfully distributed information packages to two family caregivers. I received a phone call from her that evening and documented our interaction in the following journal account:

It is 9:30pm and I have just finished a phone call with Anne who is working an afternoon shift. When I answered the call she began the conversation by saying “I’m just calling to give you the good news!” Anne was elated and explained that she had distributed information packages to family caregivers of two Residents that evening and had a third family caregiver interested in participating, who would read the information sheet and contact her tomorrow. Anne was jubilant on the phone stating: I just had to call you and tell you about our first two books!” and went on to emphasise that all of the group’s “hard work” had started to pay off.

8.2.1.2 Conduct of the Intervention

The original intentions of the group to share the responsibility for the distribution of information packages to family caregivers, in practice did not occur. Judy and
Heather (the two RNs) and the EN, Anne, had limited involvement in the action, whereas Catherine and Elizabeth (the two PCAs in the ARG) had been intensely involved. Judy explained that she distributed ‘only a small percentage’ of the information packages as her workload had largely precluded her from having the time to approach family caregivers. She stated that Catherine and Elizabeth ‘needed to’ play a central role in the intervention because she was mostly ‘tied up with medications [and] didn’t have time’ to more fully participate. Anne recalled distributing only two information packages and reported: ‘I don’t see family caregivers, these guys [referring to Judy, Catherine and Elizabeth] do. I see two ...maybe three, regular [family caregivers]’. Heather conceded that she did not distribute any of the information packages to family caregivers and explained that the demands of her role in supervisory role had impacted on her availability, reporting: ‘...it’s been really difficult for me ‘cause I’ve been mostly out of it due to different things that have been going on [in the facility]...it’s just been really tricky for me...’.

Catherine and Elizabeth explained that they approached the family caregivers ‘following the process’ outlined in the ethics algorithm. They distributed research information sheets and explained the intervention to the family caregivers. Following the receipt of a signed consent form they then distributed the information package and discussed its components with the family caregivers. Judy highlighted that the majority of research activities were undertaken ‘on the weekends’ when the unit was not as frantic compared to weekdays. Judy also emphasised that she gave Catherine and Elizabeth ‘hands-on’ support to undertake their expanded role, stating that they adopted a ‘team approach’ where she would ‘take over’ either Elizabeth’s or Catherine’s roles so that one of them was ‘free’ to discuss the intervention with the family caregiver ‘in peace and quiet’. Anne explained that on the evening shift she would follow up family caregivers who had been provided with an Information Booklet but who may not have returned the evaluation forms.

8.2.2 Analysis of data and reflection

Data collected on the impact of the intervention was generated predominately from the family caregiver evaluation forms and the group’s reflections. Initially 28 eligible caregivers were contacted to be part of the intervention. Twenty-five consented to participate, representing 89% of family caregivers on the unit. Entries on the “Family Caregiver Allocation Form” (see Appendix 29), that enabled group members to track which family caregivers had been given an information package and by whom, also
illustrated that Catherine and Elizabeth had been responsible for distributing the majority of information packages. Twenty-one of the 25 (84%) participating family caregivers returned evaluation forms. Responses to the Information Booklet are outlined below (see Table 21).

Table 21  Family caregivers responses: evaluation of information booklet (n=21)

<table>
<thead>
<tr>
<th>Questions</th>
<th>AGREE</th>
<th>DISAGREE</th>
<th>NOT SURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found the booklet to be helpful</td>
<td>100%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The booklet improved my understanding about dementia</td>
<td>100%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Helped me to understand some of the changes caused by dementia</td>
<td>100%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Improved understanding re: future decisions</td>
<td>100%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The booklet as useful in future</td>
<td>95%</td>
<td>-</td>
<td>5%</td>
</tr>
<tr>
<td>Easy to understand</td>
<td>100%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Booklet overwhelming</td>
<td>33%</td>
<td>62%</td>
<td>5%</td>
</tr>
<tr>
<td>Booklet too confronting</td>
<td>-</td>
<td>91%</td>
<td>9%</td>
</tr>
<tr>
<td>Sections of the booklet made me anxious</td>
<td>29%</td>
<td>62%</td>
<td>9%</td>
</tr>
</tbody>
</table>

Similar to the Information Booklet, the SCU Fact Sheet also received a positive response from family caregivers, as demonstrated in Table 22.

Table 22  Family caregivers responses: evaluation of fact sheet (n=21)

<table>
<thead>
<tr>
<th>Questions</th>
<th>AGREE</th>
<th>DISAGREE</th>
<th>NOT SURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found the fact sheet as helpful</td>
<td>100%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The fact sheet assisted understanding re: some of the things that you might experience when visiting the unit</td>
<td>100%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>I found the fact sheet easy to understand</td>
<td>100%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Assisted me to feel less anxious about visiting the unit</td>
<td>90%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>I found it overwhelming to read the fact sheet</td>
<td>5%</td>
<td>90%</td>
<td>5%</td>
</tr>
<tr>
<td>The fact sheet discouraged me from visiting the unit</td>
<td>-</td>
<td>100%</td>
<td>-</td>
</tr>
</tbody>
</table>
The evaluation demonstrated that 100% of respondents agreed that the Information Booklet would a useful resource for family caregivers of newly-admitted residents. Written comments to qualify this opinion further demonstrated the efficacy of the information provided. For example, respondents wrote: ‘I wish I had more information when my aunt was admitted, it was all overwhelming’; ‘[the booklet] will help them to understand how dementia progresses’; ‘excellent and explains all the stages in terms that everyone can understand’.

Similarly, 95% (20/21) of respondents indicated that they considered the Fact Sheet to be a useful resource for family caregivers of newly-admitted residents. For example respondents wrote: ‘I wish that someone had given me this simple and easy-to-read-and-understand information when I needed it’; ‘I would have appreciated receiving this information when my relative first went to the unit’; ‘…it explains the behaviours of people...[the unit] should be less confronting’.

Additionally, 81% (17/21) of respondents indicated that the Information Booklet helped them to feel more comfortable to approach staff and discuss concerns in relation to their relative. For example, respondents commented: ‘I understand the terminology of what is being discussed when I ask a question’; ‘Now that I fully understand the stages of dementia, I can ask the right questions...’ Of the four respondents who indicated the booklet did not assist them to approach staff, two reported that they already felt comfortable to approach staff. Seventy-five per cent (15/21) of respondents indicated that the Fact Sheet assisted them to feel more comfortable to approach staff and discuss concerns in relation to the care of their relative. Of the five respondents that indicated the fact sheet did not assist them to approach staff, two reported that they were already comfortable to approach staff.

8.2.2.1 ARG reflections on the impact of the intervention

Through their deliberations group members articulated the impact of the intervention across three domains; (i) changes in family caregivers’ understandings and behaviours, (ii) changes in staff-family caregiver interactions, and (iii) changes in patterns of relations amongst staff members. With the intervention strategy having been directly reliant on the actions of Catherine and Elizabeth, their narratives constitute a considerable proportion of the reflections below.
All group members explained that there was a remarkable change in how family members’ responded to staff and residents when visiting the unit. Judy reflected on the impact of the action describing it as ‘unbelievable’. She considered that family caregivers’ understandings of dementia and the special care environment had markedly improved, particularly with respect to their appreciation that residents behave in unique and sometime unpredictable ways ‘behind the blue door’.

Catherine and Elizabeth shared accounts in which they described family caregivers as being more ‘relaxed’ and less likely to approach them distressed by resident behaviours. To illustrate this change Catherine recalled an experience when a resident was acting in a particularly intrusive manner, ‘swearing and yelling’ at another resident and a visiting family caregiver. She explained that after intervening to remove the agitated resident she was surprised to discover that the family caregiver was not distressed by the event. Catherine remarked how ‘different’ this response was for this particular family caregiver.

Similarly, Elizabeth argued that the way family caregivers interpreted dementia-related behaviours had unmistakeably changed. She suggested they were generally ‘more understanding’ and were ‘more accepting’ of complex resident behaviours. Catherine agreed, reflecting on how a family caregiver who had struggled for a long time to understand his relative’s aggressive outbursts, now appeared to ‘chastise’ her less frequently. Reflecting on these apparent changes Elizabeth emphasised that family caregivers ‘actually understood’ more about dementia as result of having ‘read the book!’: She also noted that they had praised the ‘plain English’ of the information package and reported that one family caregiver voiced her appreciation of the use of ‘simple terms that she could understand’.

During their discussions Catherine and Elizabeth also extolled the benefits of the SCU Fact Sheet, noting that it had increased family caregivers’ awareness of maintaining a secure environment. For example, Catherine stated:

*Family used to say to us “they [residents] are at the door and wanting to get out, can we let them out?”…Now that seems to have stopped…They [family caregivers]…redirect or encourage [residents] away from the door.’*
Elizabeth added: ‘Before [the intervention] family caregivers used to go and let themselves out [of the SCU]; how they got the [exit] code was beyond us…but [now] they seem to come to us more’.

Elizabeth went on to argue that family caregivers ‘now…actually understand what a secure unit is’, explaining that most were now asking staff to accompany them to the exit point of the unit. For Catherine and Elizabeth the change was undoubtedly related to information in the Fact Sheet which requested that family caregivers “do not allow any person to leave the SCU…redirect the person to see a staff member…and find a staff member to assist you to the exit point of the unit” (see Appendix 19). Reflecting on these changes in family caregivers behaviours Judy asserted: ‘I’ll still never get over the complete turnaround’.

8.2.2.3 Creating a Dialogic Space – changes in staff-family caregiver interactions

Reflections of group members also illustrated that patterns of interaction between staff and family caregivers had changed. Anne recalled how she had contacted the family caregivers of two residents to invite them to participate in the research, which had unexpected effects that she described as ‘...opening up a can of worms’. To Anne’s surprise these family caregivers actively pursued conversation beyond discussing the research. She explained that they were keen to share a range of information about the residents and themselves, with one family caregiver going to great lengths to explain what life was like before her relative was placed in the SCU. Anne admitted making the assumption that the conversations would be ‘quick’, similar to other interactions she had with family. Catherine and Elizabeth shared similar accounts of how family caregivers seized opportunities to engage with them after receiving the information packages. Catherine illustrated the dramatic change when she stated, ‘they [family caregivers] would walk in [the SCU] and not speak to staff’ prior to the intervention, whereas now: ‘they are more responsive and they are more friendly’. Elizabeth asserted that family caregivers ‘know our names!’ highlighting a more interpersonal connection.

Through their critical reflections, Catherine and Elizabeth shared new understandings about their crucial role in establishing dialogic relations with family caregivers. Catherine recognised the importance of ‘personally’ approaching family members to talk with them about the information package, which she felt assisted them to ‘feel more involved’ in the unit. Elizabeth agreed and added that from her observations she
believed family members felt ‘more included’ by staff. In a subsequent meeting Anne argued that investing time to establish relations with family caregivers invited them ‘to actually open up’ and engage with staff.

8.2.2.4 Locating Practices - working in and around power relations

For Catherine and Elizabeth the magnitude of change in their interactions and relationships with family caregivers was something that they had not anticipated. As fate would have it, due to unforeseen circumstances only Catherine and Elizabeth were able to attend one of the group meetings. These two staff members therefore saw an opportunity to speak openly about their experiences of the intervention and subsequently disclosed sensitive information about the operation of power relations on the SCU. Having recognised the benefits of personally approaching family caregivers and engaging them in a dialogue, Catherine and Elizabeth reflected on how their relationships with families had been previously circumscribed. For example, Elizabeth stated:

...we were never allowed to talk to family about things like this [referring to information about dementia in the SCU]...we always had to say “look we’ll just take you to the RN”. We couldn’t make a comment; it was just one of their [RN/EN] laws...just one of their [RN/EN] guidelines.

Catherine further explained how the roles of PCAs were prescribed when she stated that conversations with family caregivers were usually ‘superficial’ about what she described as ‘little things’. Elizabeth further clarified this point when she emphasised that PCAs were not permitted to make what she considered to be simple requests of family members, such as to provide new clothes. Elizabeth reflected that nursing staff were charged with ‘full control’ over communication processes with family and this enabled them to ‘keep [their] finger on the pulse’ of the unit.

The implications of these circumstances were such that both Catherine and Elizabeth conceded that they avoided interacting with family caregivers. Catherine reported that they ‘used to sort of vanish’ when family caregivers came to the unit. Elizabeth further qualified this statement by adding: ‘in case they (family caregivers) ask [sic] something we weren’t allowed to respond to’. Recognising the effects of these conditions on their relations with family caregivers, Catherine stated: ‘I’m sure they always felt like you were fobbing them off’. Stories shared by Catherine and Elizabeth suggested that they were disaffected by their exclusion from
communicating with family caregivers. Catherine stated: ‘it wears you down after a while. It is mentally draining because you are walking on egg shells...’ Their feelings of alienation were further apparent when Catherine later reported, ‘we just got to the state where we would just back away [from communicating with family members]...we sort of just closed ranks really’.

Catherine and Elizabeth acknowledged having never previously examined how their circumscribed roles on the SCU impacted on their relationships with families. Elizabeth conceded that she had not considered such issues as important, while Catherine attested: ‘it’s just something that we are accustomed to, it’s normal’. These comments illustrate how hierarchical staff relations and role demarcation were taken for granted by the PCAs and how within these unexamined circumstances they had developed habits that ensured their isolation from family caregivers.

In a later meeting when all group members were present, Catherine’s and Elizabeth’s narratives about the demarcation of roles between nursing and care staff were substantiated by Anne. She acknowledged that PCAs generally ‘weren’t allowed’ to have discussions with family caregivers about their relative’s dementia or the care environment. This statement marked the first time during any ARG meeting where there was public acknowledgement that PCAs were effectively silenced in their interactions with family caregivers. This recognition, albeit brief, was important because it led to group members’ recognising a new collaborative ethic that had emerged through their participation in the research.

8.2.2.5 Recognising the benefits of working in collaboration- changing relations between staff members

Catherine and Elizabeth insisted that through their collaborations with other ARG members to develop the intervention strategy, their colleagues had gained a greater appreciation of the knowledge and skills they possessed. As a result, Catherine explained that she was afforded greater autonomy in her interactions with family caregivers. For example she described being given ‘full rein’ to phone family members who did not regularly visit the SCU, and provide them with an opportunity to receive an information package. While these occurrences may appear to be insignificant happenings in the milieu of everyday work, Catherine and Elizabeth considered them as highly symbolic of a more collaborative agenda with nursing staff in the ARG.
Anne and Judy corroborated this opinion when they reflected on the benefits of having supported Catherine and Elizabeth to be more autonomous in their interactions with family caregivers. Anne stated: ‘Well the care staff can answer quite a few questions and relieve a lot of anxiousness [for family]’. Reflective of the development of more collaborative relationships with the PCAs, Judy attributed the success of the intervention to a ‘team approach’. Elizabeth agreed, highlighting that her confidence in assuming more autonomy was largely based in the knowledge that she ‘had back up’ from more senior staff. To illustrate the importance of working collaboratively with nursing staff Catherine stated, ‘I feel more comfortable in approaching them [family caregivers] and being out on the floor amongst them [family]...I feel more at ease and more confident with what I say’.

Underpinning these staff members’ emerging sense of empowerment was a recognition that their relations with their colleagues were more equitable. Elizabeth stated that she felt ‘more valued’ and ‘more useful’ having been supported to take on an expanded role. Catherine highlighted that she felt ‘more equal’ with nursing staff in the ARG.

The group members’ reflections on Action Cycle 5 revealed a new appreciation of collaboration between nursing and care staff in fostering the development of positive relationships with family caregivers. This was an important finding as the next action cycle, which involved trialing the PAM strategy, provided further opportunities for the development of collaborative relations between nursing staff and PCAs.

8.3 Post-script: measures for sustainability

Through their collaboration and informed action, the ARG members brought about a number of improvements in practice. Reflecting on the positive outcomes from the education sessions, group members were optimistic that they could integrate the session within the existing educational framework at the facility. This approach meant that a senior staff member would be responsible for co-ordinating future education sessions and encouraging staff attendance. Heather and Anne planned to continue to deliver the sessions. They intended to liaise with management to facilitate the continuation of education sessions after the completion of the study.

There was unanimous support amongst group members for the ongoing distribution of information packages to family caregivers beyond the completion of the project. It was recognised however, that to ensure sustainability, the distribution of the
information resources needed to be formally incorporated into existing facility processes. The ARG members were keen that other staff on the SCU has access to the information resources and were encouraged to talk to family caregivers about the resources. This was seen by the group as a step towards opening up greater possibilities for establishing dialogues between staff and family caregivers about their information needs. Therefore, at the group’s request (while they continued with Action Cycles 6 to 8), I liaised with management to formalise a process that would ensure SCU staff and family members could access the information resources.

The facility processes for admission documentation were modified so that:

- A post-admission letter sent to family caregivers 6 weeks following their relative’s admission to the SCU included a copy of the SCU Fact Sheet – this process would be facilitated through existing administrative procedures at the RACF.
- Family caregivers would be informed about the information booklet in the post-admission letter and encouraged to approach a regular staff member on the SCU if they wanted to obtain a copy.
- SCU staff would be notified by the facility management at their regular staff meetings about the aforementioned changes and informed how they could access copies of the Information Booklets in the SCU and provide them to family caregivers.
- An electronic version the Information Booklet and the SCU Fact Sheet were provided to the facility administration staff who would be responsible for printing off copies of the resources. With the resources being stored centrally, staff would be able to order copies through existing processes for obtaining stationary from administration staff. In this sense the provision of information to family caregivers was not dependent on the continued presence of ARG members on the SCU.

8.4 Discussion

The findings of this stage of the study first and foremost illustrate how the ARG members had become proficient in their roles as “co-researchers” (Heron & Reason 2001, pp.144-145) or what Dewing and Traynor (2005, p. 701) referred to as “practitioner researchers”. As they took action to address the information and knowledge-related needs of staff and family caregivers, they collected data, kept
field notes and met to critically reflect on their progress. I continued to resource the ARG by providing them with case notes from their meetings and undertaking the initial analysis of the evaluation data collected for each intervention. However, my role had also changed. I functioned more as a “critical companion” (McCormack et al. 1999, p.260) with the group members. At the end of each intervention we discussed the incremental changes that had been achieved. During these discussions I listened carefully to group members’ reflections and prompted them to critically consider previously unexamined aspects of their actions. In keeping with Wadsworth (2001, p.330), I accompanied the group as they shared and revisited their stories, and arrived at “transformative moments”.

Through the reflections of the group members the impacts of resource constraints and organisational hierarchy on their actions were revealed. Consistent with the literature (Phillips et al. 2006; Strumpf et al. 2004; Maddocks et al. 1999; Froggatt 2000a), issues of short-staffing and high resident-to-staff ratios constrained the capacity of SCU staff to support an agenda promoting a palliative approach. This was most evident during the group members’ reflections on Action Cycle 4. They highlighted the inability of some SCU staff to attend the education sessions due to an absence of backfill on the unit. Research (Phillips et al. 2008) reporting on a multi-faceted intervention study, aimed at supporting aged care staff to implement a palliative approach, identified similar organisational barriers inhibiting staff (in particular RNs) from participating in palliative care education sessions. Literature published after the completion of this study by Fleming and Fitzgerald (2009), about the roll-out of a national dementia training program in Australian RACFs, has confirmed that finding staff to replace those who are to attend education continues to be an obstacle to implementing evidence into practice in the RAC setting.

Despite facility management providing funding for staff to attend the research education sessions, the findings of Action Cycle 4 suggest that financial reimbursement alone was not enough to encourage staff participation. In what is a complex socio-political context, staff who work within a network of hierarchical power relations, had historically been directed to attend certain education sessions by management. Therefore, it was perhaps not surprising that in the absence of this direction, attendance at the education sessions was interpreted by some staff members as being of limited importance. These findings like others (Jervis 2002) suggest that the operation of hierarchical power relations was embedded within the
organisational fabric of the facility. So familiar were these relations to staff members that their motivation to participate in a half-hour education session was dependent on the exercise of power by management. However the taken-for-granted nature of these “relations of dependence” (Crotty 1998, p.143) meant that management were seemingly unaware of the significance of their support in promoting staff involvement in research activities. These findings, consistent with the work of others (Lyon 2007; Grieve 2006) emphasise the importance of facility management being engaged with, and advocates of, research as a strategy to foster the development of evidence-based practice.

Amidst these competing material-economic and political tensions, the importance of ARG members working in partnership with each other to implement a change agenda was a key finding that emerged from this stage of the study. As previously noted in Chapter 2, aged care staff experience professional isolation characterised by limited opportunities to engage with colleagues in the same facility as well as their peers in other settings (Jones & Cheek 2003; Venturato et al. 2006; Miskella & Avis 1998; Robinson et al. 2005a; Hasson et al. 2008; Avis et al. 1999). Therefore, the opportunity to work together marked an important transformation in the relationships between the ARG members in this study. The significance of “partnership working” fostered through participatory, action-orientated approaches has gained increasing significance (Nolan et al. 2007b; Froggatt et al. 2009; Nolan et al. 2002b) within the past decade as a strategy(s) to promote practice change.

The provision of ARG-led education sessions for SCU staff was a material expression of the group members working in partnership. This intervention provided opportunities for them to challenge the historically constructed boundaries of their roles and assume positions that would support the development and delivery of a palliative approach to care. Herein, the group members shifted from being passive recipients of information provided by others (e.g. management staff, external agencies) to proactively pursuing an educative agenda. The opportunity for the group members to meet, share stories and arrive at a “consensus” (Habermas 1984, p.284) for their plans of action facilitated their critical analyses of entrenched assumptions about their scope of practice on the SCU. Consistent with the literature (Barrett 2001) that has reported on the empowering potential of collaboration, Action Cycle 4 illustrated how the ARG members were provoked to think about their own skills and expertise differently, having greater recognition of their own value as employees.
These findings support those in the literature (Aveyard & Davies 2006; Wilkinson et al. 2009) who attest to the utility of critical, action orientated methods in revealing anew to practitioners the extraordinary aspects of what may have once seemed completely ordinary, so that they may approach practice in radically different ways.

The positive outcomes of the ARG-led education sessions were evident in the feedback from the participants’ evaluations. The data indicated improved staff member understandings around a palliative approach, a greater awareness of the Guidelines (ADoHA 2006) and an appreciation by staff of the opportunity to access information and evidence. These findings support the work of Froggatt (2000a) and more recently, Phillips et al. (2008), in demonstrating the effectiveness of providing targeted education about palliative care to RACF staff. This study illustrates that promoting opportunities for developing practitioner-driven educative agendas can foster education that is sensitive to the complexities of the local context. The use of resident case studies and an interactive approach to the education sessions provided a dialogic space for participants to talk about sensitive issues of death and dying. In RACFs where communication about issues of mortality are rare, if not “taboo” (2006, p.238), providing opportunities for aged care staff to share their understandings in a supportive forum, away from the every-day milieu, may contribute to more open discourse about death and dying (O’Connor 2009; Watson et al. 2006). In support of this contention, Abbey et al. (2006, p.59) have argued that the difficulties in the implementation of the Palliative Approach Guidelines (ADoHA 2006) illustrate the need for tailored contextually-specific education.

A potential weakness of the evaluation data, which supports the success of the education sessions, is that it relied on self-report from the participants, rather than more objective measures. This problem has previously been highlighted in implementation research (Froggatt et al. 2006; Prior et al. 2008). More objective measures of knowledge or practice change were not collected by the ARG members when participants returned to practice after the education sessions. Further evaluation such as this would have improved the validity of our findings and provided an indication of the impact of the education session beyond the immediate results.

Further benefits of the ARG members working in partnership were evident in the success of Action Cycle 5. Through taking informed action to address the information and support needs of family caregivers, ARG members were able to develop more positive and meaningful relationships with family caregivers. There is
a significant body of evidence that highlights the benefits of collaborative relationships between RAC staff and family caregivers (Nolan et al. 2004; Nolan & Dellasega 1999; Mass et al. 2004; Kellett 2000; Woods et al. 2008; Lau et al. 2008; Haesler et al. 2006, 2007). However, as pointed out within the literature (Haesler et al. 2006, 2007; Nolan et al. 2002b) findings are equivocal about the most effective strategies that can be implemented by aged care staff to promote relationship development.

Through their critical reflections on their changed relationship with family caregivers, Catherine and Elizabeth revealed a greater awareness of how institutional hierarchy historically precluded the development of collaborative relationships with families. These reflections illustrated that despite being “frontline caregivers” (Whittaker et al. 2007, p.41) their capacity to engage with family members was limited by historically constructed role boundaries that supported nursing staffs’ authority over communication and information transfer with family caregivers. Dowding and Homer (2000) suggested similar circumstances with respect to the exclusion of PCAs from communication processes. Research published after the completion of this study, investigating educational needs of staff around end-of-life care, also has confirmed that PCAs avoid engaging with families about issues of palliative care (McDonnell et al. 2009). Role demarcation and PCAs’ uncertainty about communication boundaries with family caregivers have been identified as significant obstacles to improving palliative care provision in RACFs (McDonnell et al. 2009; Ersek et al. 2000; Ersek et al. 1999). Catherine and Elizabeth’s reflections highlighted how the exercise of power by nursing staff to marginalise their engagement with families was disempowering and often left them feeling despondent about their role. However, their subsequent accounts of taking action to avoid family caregivers were suggestive of their own complicity in this hegemony. Here, the exercise of power both by nursing staff and PCAs can be understood, as Gaventa and Cornwall (2001) might have explained, to be shaping the possibilities for family caregivers actions on the SCU. Taken from this perspective, the capacity of family caregivers to contest care processes and negotiate greater involvement, which would inevitably disrupt staff routines, was limited.

The reflections of the group members revealed how hierarchical relations between staff members had become part of what Foucault (1988, p.10) might call their “most familiar landscape” of practice. The invisibility of this network of power relations
was a key obstacle to the development of partnerships with family caregivers that could reflect a “relationship-centred” (Nolan et al. 2004) approach to care. Arguably, the findings of this study suggest that the development of practice to support a palliative approach requires that aged care staff have an appreciation that caring for people with dementia and their family caregivers occurs in the context of relationships (Nolan et al. 2004). Herein, the interactions, information exchange and shared understandings between different staff, family carers and residents is considered to be integral to the quality of care (Nolan et al. 2004). In this study the process of taking action created an opportunity for the ARG members to work together to challenge their hierarchical relations and redefine the boundaries of their roles. This reconfiguration of power relations enabled them to pursue more inclusive relationships with family caregivers.

The development of more equitable power relations between the PCAs and nursing staff was evident in the comments of Catherine and Elizabeth as they described feeling ‘more equal’ with the nursing staff, ‘more valued’ in their roles, ‘more useful’ to family caregivers and having made an ‘important change’ that they could build on in the future. In keeping with the perspectives of Nolan and colleagues (2007a, pp.195-196), these findings suggest that through a collaborative and participatory research approach, these ARG members experienced a “sense of support” to pursue change in their practice; a “sense of belonging” to a team where their contribution was valued and recognised; a “sense of achievement” of having delivered “good care”, and a “sense of continuity” in that their reflections on the historical construction of relationships informed improvement in their current care practices. Catherine and Elizabeth connected their sense of empowerment and their new found confidence in interactions with family caregivers to working in partnership with nursing staff, rather than in isolation.

The family caregiver evaluation forms provided evidence of the positive contribution that the action had made in meeting their information needs and improving their capacity to engage with staff members. Previous research has demonstrated that family caregivers desire staff to voluntarily provide information about the resident’s condition and their care, rather than having to actively seek this out (Nolan & Dellasega 1999; Hertzberg & Ekman 1996; Marquis et al. 2004; Hertzberg & Ekman 2000). Accordingly, the ARG’s reflections demonstrated that by the PCAs personally and proactively approaching family caregivers to provide them with the information
packages promoted the establishment of more collaborative relations. This finding supports those of Wilson, Davies and Nolan (2009), who reported that creating opportunities for regular personal interaction could promote the development of “reciprocal relationships” between staff, family and residents. The data from the evaluations and the ARG reflections suggested that the intervention also provided a “sense of significance” (Nolan et al. 2007a, p.196) for family participants who seized on opportunities to talk with staff about their relative and be involved in the information sharing. Likewise, for ARG members the establishment of more meaningful and less vexed relationships with family caregivers was a highly significant improvement, enabling opportunities for “mutual appreciation” (Aveyard & Davies 2006, p.101) of each other’s roles.

While the findings of Action Cycle 5 are contextually specific and emerge from a small group of staff and family caregivers, they are clearly not intended to be generalisable. However, they do demonstrate the effectiveness of action research in disrupting dominant power relations, which in turn can promote possibilities for staff to reconstruct their relationships and practices to better meet the needs of those people to whom they provide care. To this end, strategies that facilitate what Davies and colleagues (2007, p.51) have described as “some blurring of roles”, especially across historically rigid role boundaries, can support previously marginalised staff (such as PCAs) to practice with greater autonomy. Through improved partnerships between aged care staff members, the provision of an evidence-based palliative approach to care can be enhanced.

Overall, the findings for Action Cycles 4 and 5 confirm the importance of providing opportunities for aged care staff to participate in sustained democratic forms of dialogue. The group members’ greater appreciation of their different skills and capabilities, as well as a deeper awareness of the socio-political and material conditions that undermine evidence-based practice, energised them in their roles as “practitioner researchers”. The success of Actions Cycles 4 and 5 propelled the group into Action Cycle 6.
Chapter 9: Taking action to support evidence-based practice: part II

Having achieved a range of positive outcomes during Action Cycles 4 and 5, the group members enthusiastically progressed to address the issues identified in relation to pain management and palliative care planning practices of SCU staff. As indicated in Figure 22 below, Action Cycle 6 focused on piloting a collaborative PAM strategy. In Action Cycle 7 the group members revisited concerns about palliative care planning that were raised in the preliminary investigation and explored strategies that would enhance their abilities to engage in case conferences with family caregivers. Finally, Action Cycle 8 reports on the ARG’s attempts to pilot a palliative care case conferencing intervention.

**Figure 22 Action Cycles 6-8**

<table>
<thead>
<tr>
<th>Action Cycle 6</th>
<th>Pilot collaborative PAM strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Action Cycle 7</td>
<td>Networking expert support</td>
</tr>
<tr>
<td>Action Cycle 8</td>
<td>Pilot palliative care planning intervention</td>
</tr>
</tbody>
</table>

*9.1 Action cycle 6 – Pilot pain assessment and management (PAM) strategy*

**Figure 23 Action Cycle 6**
The PAM strategy had been designed by the ARG members to address the limited use of formal pain assessment processes in the SCU and problems with collaboration between nursing staff and PCAs in pain management practices. Data from the preliminary investigation supported the absence of a best practice approach to the assessment and management of pain. The majority of planning for this intervention had occurred during Action Cycle 2 (Chapter 7) whereby the group members developed a PAM form (Appendix 25) and agreed to introduce SCU staff to the PAM strategy during the staff education sessions conducted in Action Cycle 4. At this time they planned to invite the staff members to participate in a pilot of the PAM strategy. The intention of the action was that PCAs in the SCU could formally undertake an assessment of a resident who they suspected was in pain, using the Abbey Pain Scale (2004). These staff members could then document their assessment on the PAM form, prior to consulting with the nurse on duty who would either confirm or reject the assessment. The RN/EN would be responsible for suggesting appropriate interventions and a follow-up assessment (post-intervention) could be conducted by the PCA or RN/EN. Figure 24 provides a summary of the ARG’s action plan including strategies for monitoring and evaluating the intervention.
Problem
Pain assessment and management processes not consistent with best practice standards

Constitutive Concerns
- Concerns that residents’ pain is not adequately managed [Reconnaissance: ARG discussions].
- Limited use of formal pain assessment tools to assess incidental episodes of pain. [Action Cycle: audit findings, criteria 2.4]
- Informal strategies of pain assessment and information transfer. [Action Cycle 1: ARG Collaborative analysis]
- Limited documentation relating to the outcome of interventions to manage pain [Action Cycle 1: audit findings, criteria 2.4]
- Problems in collaboration between PCAs and Nursing staff in facilitating pain management [Action Cycle 1: ARG Collaborative analysis]

Strategy for Action:
- Information session to introduce staff to the PAM protocol and PAM form provided after education sessions to occur in Action Cycle 1.
- Pilot collaborative pain assessment and management strategy, including PAM form, for four Residents over a period of three months.
- PCAs will be able encouraged to document assessments on the PAM form, using the Abbey Pain Scale (Abbey et al. 2004).
- Assessments will need to be confirmed by nursing staff member and intervention documented by either PCA or nurse as appropriate (e.g. PCAs could document the application of a heat pack; RN/EN would document administration of medication).
- Follow-up pain assessment conducted, ideally by the PCA who did the first assessment and documented on PAM form.
- PAM forms stored on the SCU in a specially labelled folder that staff will be able to access. An example of a completed pain scale will be included within the folder as a prompt to assist staff.

Monitoring:
- Record research group meetings. The ARG will meet will meet after one month of the pilot to discuss the progress of the action and identify issues which need to be addressed.
- Researcher’s Journal and field notes
- ARG members field notes

Data Sources:
Research group case notes
Completed PAM forms
Researcher’s journal

Analysis:
Collaborative thematic analysis of ARG case notes.
Audit of PAM forms for quality and completion.

9.1.1 Take action and collect data

After having planned the PAM strategy during Action Cycle 2, the group members had sought feedback from the project steering committee about their proposal in Action Cycle 3. Based on recommendations from the committee (see p.208) the
group members made minor modifications to the PAM strategy and accompanying form.

A folder containing a protocol for the PAM strategy (Appendix 30) that staff could consult as well as blank copies of the PAM forms were placed in the nursing station in the SCU alongside other documentation frequently accessed by staff. A memo was posted on the staff notice board indicating that the pilot of the PAM strategy had commenced and outlined where the PAM forms could be located. As only one RN had attended the PAM education conducted as part of the earlier Action Cycle 4, the memo alerted nursing staff to review and familiarise themselves the PAM protocol. As planned, ARG members talked to those PCAs who attended the education sessions (in Action Cycle 4) about the intervention and encouraged their participation.

The ARG members were unable to reconvene to discuss the progress of the intervention until 2 months after its commencement due to problems with staffing and availability. At this meeting, group members’ accounts suggested that the PAM intervention was not going to plan. They reported that staff members outside the ARG had not contributed to piloting the PAM strategy. This raised serious concerns about the feasibility of the action for the group members. While the lack of participation was disappointing, the ARG members were reluctant to discontinue the intervention inside the planned three month pilot period. They decided to continue with the intervention for another month, during which time they would investigate reasons for the poor participation rates. The group members kept field notes of their findings and these are reported below.

9.1.2 Analysis of data

As discussed in Chapter 6 the evaluation of this action was based on an audit of the PAM forms and the analysis of field notes of ARG members. In summary, the findings of these analyses indicated:

- Three residents were commenced on PAM forms across the three-month pilot period.
- A total of 15 episodes of pain were recorded.
- Two residents had only one episode of pain recorded on each of their PAM forms.
• One resident (John) had 10 episodes of pain and intervention strategies were documented.

• Catherine was the only PCA to document on a PAM form, the remainder of episodes were documented by Judy and Anne.

The majority of data collected during the piloting of the PAM strategy was for one resident, John, who the group members identified has ongoing problems with pain. These results are detailed below.

Data on John’s PAM form indicated that he was assessed across a 7 day period. A total of 10 episodes of pain were recorded, however Judy and Anne were the only two staff members who documented on the form. Figure 25 shows graphically each episode of pain that was noted on the PAM form. Each episode contains two different data points. The first data point is John’s pain score on initial assessment prior to intervention; the second data point is the pain score on reassessment, 30-60 minutes after intervention. For example, episode one that is highlighted on the graph demonstrates that John had an initial Abbey Pain Score of seven (mild pain) when he was assessed and following analgesia it remained the same. However, when John was re-assessed later in the shift his pain was scored at seven and following analgesia it was reported as resolved (e.g. episode 2).

**Figure 25  Pilot of PAM form for one resident**

![Pain Score Graph](image)

Figure 25 shows that John had mild or moderate pain on each day that he was assessed. The PAM form made it possible to track John’s pain and his response to interventions at selected points during the day and across time. For example, the episodes of pain rated six or above all occurred between 7.00am and 12 noon, the
majority of which occurred between 7.00 and 8.00am – the time when he would usually have been assisted out of bed and had his hygiene attended to. Other entries on the PAM form indicated that John had predominately mild pain in the afternoon and evenings, scoring five or below on the Abbey Pain Scale. For each episode of pain John’s non-verbal and behavioural cues were also documented. These entries included: ‘frowning’, ‘resistive to being moved’, ‘reduced mobility’, ‘slow mobility’. Observed changes to his behaviour following analgesia were also documented by the staff such as ‘now mobilising’, ‘not so unsteady’, ‘ambulation improved, smiling’.

The shaded areas in Figure 25 represent that there was no documentation on the PAM form for 3 days (20/06/07 to 22/06/07). Interestingly, these dates corresponded to Anne and Judy’s days off.

The entries on the PAM form demonstrated that John’s pain scores decreased and his behaviour and mobility improved when he was administered regular analgesia. Towards the end of the assessment period Judy had written on the PAM form that she had requested John’s GP to prescribe regular analgesia on the basis of the information collected. The following day Judy had documented on the form that John had been commenced on this regular analgesia. Across the following 6 days there was only one episode of mild pain recorded that improved after the administration of the regular analgesia he had been ordered. Twelve days after John had been commenced on regular analgesia Judy discontinued the PAM form. She documented the following comments at the bottom of the form: ‘John is more responsive...more friendly especially with female residents and staff, conversing more, laughing, ambulation improved... is now wandering and stopping at the nurses’ station to give us a smile’.

9.1.3 Reflection

During their initial reflections, group members discussed that the pilot of the PAM strategy had yielded a ‘positive outcome’ for one resident, John. Judy indicated that regular documentation on the PAM form had enabled her to accumulate evidence of John’s ongoing issues with pain and had been effective in assisting her to, as she described, ‘pin down’ his GP and obtain an order for regular analgesia. Catherine and Elizabeth emphasised that John’s quality of life had improved with his revised pain management. For example Catherine stated, ‘John has...been put on [analgesia] three times a day...and he’s turned right round...he’s up walking, smiling, communicating more, he’s opened up’. She asserted that as a result of using the PAM
strategy John was no longer ‘locked in [his] body’. Elizabeth agreed stating categorically that John had ‘improved’. Notwithstanding this positive result, the group members also highlighted how the presence of cognitive impairment added to the complexity of assessing individual resident’s pain status. Elizabeth explained: ‘different residents do different things to show their discomfort and sometimes it’s like we have to do detective work...and that takes a while’.

It was evident from the group members’ reflections that they believed the PAM strategy held great potential to improve the pain management of residents, as it encouraged more formal documentation of assessment and intervention strategies. However, given that no staff members outside the ARG participated in the pilot, little data were collected. The majority of the group’s reflections therefore, focused on analysing why the intervention had been unsuccessful at engaging the PCAs and RN who had attended the education session about the PAM strategy. These discussions revealed emerging understandings about the range of resourcing and socio-political conditions that impacted on the ability of staff to change their practices.

9.1.3.1 Conditions constraining the conduct of action: perceptions about staff responses to change

Group members initially attributed the lack of staff participation to a general sense of apathy. For example, Anne suggested that in her experience staff were largely disinterested and at times recalcitrant to practice outside their routines and habits. To support her opinion she recounted comments made by a RN during the conduct of the pilot that were less than enthusiastic. She stated: ‘I handed it [the PAM folder] to her [the RN], she opened it up and she said, “Oh well I don’t know what’s going on.... why do you bother?”’

Catherine shared similar sentiments to Anne about the poor participation of PCAs when she said ‘...there is (sic) PCAs with a lot of negative attitudes...they just put a barrier...put their back up’. Heather claimed that staff members’ disinterest in change was not new phenomenon and stated: ‘It’s just that same old thing...there’s only a couple of them [staff] that are really interested, and you know, the majority of them just aren’t’. Indeed, Heather later attributed the lack of staff participation in the intervention to what she described as ‘bloody laziness!’.

As the ARG’s discussions progressed it was suggested that staff despondency to change in the SCU was most likely related to the cumulative effects of staffing
pressures and heavy workloads. For example, Judy stated: ‘...we’ve been regularly short [staffed]...you come in the next morning and...we’re all feeling flat, and you say “Oh no, not again”’. It was at this point in one of the group meetings that the discussions shifted and the group members more closely interrogated the impacts of staffing and workloads.

9.1.3.2 Acknowledging material constraints

There was consensus amongst the group members that staffing levels in the SCU were a crucial factor undermining the volition of staff to participate in the intervention. Judy argued that during periods of short staffing, having to complete extra documentation associated with piloting the PAM form exacerbated already heavy demands. To explicate this point she highlighted that Catherine and Elizabeth had not ‘had a chance’ to adequately engage in the intervention because of their heavy workloads. Catherine agreed with Judy and emphasised that being responsible for the care of ‘12 residents’ when the unit was short staffed, effectively precluded her from participating in the research activities. In support of the group members’ accounts Anne stated that extra documentation was ‘time consuming...’ emphasising that when there was not adequate staff in the SCU: ‘the normal everyday charts don’t get filled in’.

As the ARG members shared their stories it became evident that resourcing issues, with respect to staffing and workloads, were reminiscent of concerns that members raised during their reconnaissance discussions. Reflecting on this synergy, they resolved that the lack of staff participation in the PAM strategy pilot was the result of complex issues. Hence, earlier accounts about recalcitrant and lazy staff no longer provided an adequate rationale about why the intervention had not achieved its goals. Epitomising this shift in understanding Anne revisited her perceptions about the intervention and suggested that staff non-participation was not because they ‘want to be ignorant’; rather she acknowledged that ‘a lot’ of reasons underpinned the limited success of the intervention. This alternative way of understanding the situation became progressively evident during the group’s reflections on the politics of providing care in the SCU and the implication of these conditions for the success of the intervention.
9.2.3.4 The politics of care: the impact of hierarchical relations

As the ARG members continued to interrogate the outcomes of the intervention, they developed an analysis about how hierarchical relations between PCAs and nursing staff had been a barrier to initiating practice change. Heather explained that, based on her observations and interactions, although nursing staff on the SCU had expressed support for the intervention, they did not operationalise this or actively promote PCAs’ participation in piloting of the PAM strategy. She stated:

*The impression I got was that they [PCAs] felt isolated and what they had to say, what they had observed and what they wanted to contribute to the [PAM] process was not valued or supported [by nursing staff].*

Catherine agreed with these sentiments and suggested that despite the group’s efforts to implement change, hallmarks of ‘normal practice’ in the SCU had prevailed, which she described as nursing staff remaining ‘in control’ of pain assessment and management. Elizabeth suggested that nursing staff had not participated in the research because in her opinion ‘it would bring them down to our [PCA’s] level’. Accordingly, such circumstances would have threatened the status quo of relationships between nursing staff and PCAs on the unit. Anne reflected that when working within such circumscribed relationships, PCAs on the unit ‘...don’t feel confident’ to formally voice concerns about a resident’s pain, without the explicit support from the RN or EN in charge of the shift.

Subsequent reflections by Catherine and Elizabeth revealed that a general lack of collaborative relationships between PCAs and more senior facility staff had significant and unexpected effects on the research agenda. Elizabeth explained that there had been a delay in the payment of those staff that attended the education sessions (Action Cycle 4), as a result of an administrative mistake. In response to this situation some PCAs had refused to be involved in the PAM intervention. Elizabeth shared one of her journal entries with the group in which she had documented comments relayed to her by these PCAs: ‘I was told by [PCA] “not doing it [participating in the action], I didn’t get paid to attend the session”’. Catherine reported similar experiences of resistance by care staff. However, this somewhat activist reaction by PCAs had not come to the attention of the group members until they had almost reached the end of the three-month pilot phase. In a later meeting, this situation provoked Elizabeth to critically reflect on the efficacy of strategies.
employed by PCAs in the SCU to demonstrate their dissatisfaction. Indeed, she considered silent resistance as somewhat futile and stated that historically PCAs: ‘...[have] never come out and said anything [to the nursing staff]’ in relation to circumstances that caused them dissatisfaction. Consequently, she suggested that such situations were extremely difficult to remedy when one party, in this case nursing staff ‘remain in the dark’. With a growing recognition of the fragmented relations between nursing staff and PCAs in the SCU, the group members raised serious concerns about their ability to instigate practice change that relied on collaborative action. Therefore, at the end of the three-month pilot the group members chose not to continue implementation of the PAM strategy. With an awareness of the need for more fundamental work to build collaborative staff relationships, group members recognised that they did not have the scope or the time within the project to address this issue. With a much greater awareness of the socio-political context that constrained the capacity of staff members in the SCU to implement practice change, the ARG progressed to make a range of strategic decisions about the last area of action that they planned to pursue.

9.2 Action cycle 7: palliative care planning: networking expert support

As previously discussed in Chapter 7, the ARG members engaged in some preliminary planning activities (Action Cycle 2) with respect to the palliative care planning intervention. These activities were principally directed towards modifying a POT form to be trialed in place of the existing palliative care planning form. The group members also developed an information sheet for family caregivers and shared some cursory ideas about conducting case conferences with families. These initial discussions resulted in Judy volunteering to oversee the conduct of an intervention where case conferences would be trialed with family caregivers of 15 SCU residents. During these initial discussions PCAs were not envisaged as having a role in attending case conferences.

Towards the end of their planning activities in Action Cycle 2 (April 2007), the group members made a pragmatic decision to delay further activity on palliative care case conferencing until they had implemented the other three intervention strategies. By the end of September 2007, the ARG members had progressed through six action
cycles (Figure 26) and developed increasingly sophisticated understandings of the action research process and their own practice.

**Figure 26**  **Action Cycle 7**

This section addresses the participation of ARG members in two action cycles associated with developing and implementing palliative care case conferencing on the SCU. Action Cycle 7 focused on the development of networks with experts who could assist the group members to plan and conduct case conferences. In Action Cycle 8 palliative care planning case conferencing was piloted in the SCU.

**9.2.1 Replan**

Following the research steering committee meeting a number of recommendations (Chapter 7, p.208) were made with respect to the proposed intervention. During the meeting it was suggested that ARG investigate the possibility of accessing the Respecting Patient Choices Program (RPCP) (2007), at a nearby hospital, to help equip them to engage in discussions with family caregivers about palliative care issues. Secondly, the committee also recommended that the ARG seek legal advice about the POT document that they had modified to ensure that it contained legally appropriate statements and preamble.
In response to these recommendations group members met to plan how they would go about accessing the aforementioned information. Due to their limited availability they decided that the most expedient method of seeking legal feedback about the POT was for me to contact the Public Guardian and seek the relevant advice. I was also the only member of the group who was familiar with the RPCP activities; therefore the group also requested that I make contact with the RPCP educator. The Action Plan for these activities is summarised in Figure 27.

**Figure 27  Action Cycle 7 - Action plan**

**Problem:**
Further planning required to develop palliative care case conferencing intervention.

**Constitutive Concerns:**
- Concern raised at the steering committee meeting that the POT contain legally appropriate language before it is trialed [Steering Committee meeting].
- Steering committee suggested that ARG members access RPCP to assist them to facilitate advance care planning case conferences [Steering Committee meeting]

**Strategies for action:**
Establish networks with experts to facilitate the development of the palliative care planning intervention strategy and its implementation. As agreed by the ARG:

a) Sharon will be responsible for contacting the Public Guardian and arranging a meeting, where she can discuss the POT and receive feedback about legal aspects of the form.

b) Sharon will contact the RPCP educator and investigate whether member of the ARG can access RPCP education which would assist them to facilitate discussion with family caregivers about palliative care planning and end-of-life care. Sharon will report back to the ARG following the above activities and provide relevant feedback and if applicable, organise dates for education session(s) with RPCP educator.

**Monitoring:**
- Record research group meetings during networking activities and develop case notes.
- Researcher to keep journal/field notes.
- ARG members to keep field notes/journal.

**Data sources:**
- Research meeting case notes
- Researcher’s journal and field notes
- Field notes from meeting with Public Guardian

**Analysis:**
- Collaborative thematic analysis with research group of research meeting data.
- Collaborative analysis of field notes from meeting with public guardian.
- Thematic analysis of researcher field notes
9.2.2 Take action and collect data

9.2.2.1 Consultation with the Public Guardian

In response to the group’s requests I organised a meeting with the Public Guardian, and when we met I kept field notes that outlined our discussions. I recorded the following:

- **Public Guardian discussed that the POT was a legally binding document under common law.**
- **Public Guardian suggested that the ARG include information on the Advance Care Planning Information Sheet for family caregivers about who is considered the ‘person responsible’ according to the Guardianship and Administration Act 1995 (TAS) and thus able to make health related decisions on behalf of a non-competent person.**
- **Amend POT to clearly delineate whether the family caregiver is an ‘enduring guardian’ or ‘person responsible’ and reword preamble to indicate scope of responsibilities of family caregiver as the ‘person responsible’. For example: (i) to act in the best interests of the care recipient, (ii) acknowledge whether there is a prior ‘statement of wishes’ made by the person with dementia.**

The POT and Information Sheet were modified over the course of two meetings, and final versions of these tools are contained the Appendices 26 and 27 respectively. During this time I also accessed an educator from the RPCP (2007) at a nearby hospital who agreed to conduct an education session with the group about key issues associated with advance and end-of-life care planning.

9.2.2.2 Building capacity of group members: accessing RPCP Education

On the day the RPCP educator planned to meet with the ARG, staffing conditions at the facility precluded the attendance of Anne and Judy and Heather was away on sick leave. Only Catherine (PCA) and Elizabeth (PCA) were able to attend the education session. I noted in my journal that:

...the facility was short staffed across all units, and as such Anne and Judy were required to remain on the floor. At the time of the education session the afternoon profile of nursing staff consisted of only one RN who was supervising across five units and one EN who was able to assist on one unit.
for four hours. Heather was on sick leave and management were searching for more staff (Researcher Journal September 2007).

The education sessions lasted between one and two hours and were conducted in an interactive format and covered the following topics:

- ACP, importance and different types of advance care plans;
- Key considerations to success in ACP;
- Capacity and ACP;
- Enduring Guardianship and substitute decision-makers;
- Burden versus benefits of treatment and what to discuss around treatment choices;
- Instruments for end-of-life decision-making;
- Legal and ethical considerations; and
- Dying with dignity guidelines.

A second education session was organised and all group members were able to attend (Catherine and Elizabeth for a second time). There was no formal evaluation of these sessions. Instead, the group members chose to meet and discuss their perceptions.

9.2.3 Analysis and reflection

When the ARG members met towards the end of Action Cycle 7 their reflections were focused on the RPCP education sessions. Group members engaged in very little reflective discussion about receiving feedback from the Public Guardian with the exception of agreeing that the modifications to the POT and Advance Care Planning Information Sheet were appropriate and improved the useability of the documents.

Group members were in agreement that the RPCP education sessions provided ‘very useful’ opportunities to discuss issues about palliative care planning for residents. Elizabeth described the education session as ‘really good’ and ‘really important’ in facilitating her understandings of the importance of ‘care staff being involved’ in care conferences. Catherine and Elizabeth’s request to attend the education session a second time reflected their appreciation of having a forum to discuss such issues. It was evident from Catherine and Elizabeth’s comments that they had a new conviction as to the importance of their involvement in case conferences with family caregivers. For example, Elizabeth emphasised that PCAs had a legitimate role in contributing to the palliative care planning conferences, stating: ‘...I feel that carers
should be in on it, because the carers are the ones that are doing the work...that know the ins and outs of these residents’.

Catherine emphasised the importance of approaching this last intervention as ‘a team’, like they had done in the previous action cycles. At this point Anne agreed that the involvement of the PCAs would be beneficial given they were largely responsible for facilitating continuity of resident care.

Reflecting on the benefits of the RPCP education stimulated the group members to revisit their initial ideas about the implementation of palliative care case conferencing in the SCU. Illustrative of their greater appreciation of the considerable time investment that each case conference would require, group members recognised that their earlier plan to conduct case conferences with family caregivers of 15 residents was not a realistic goal. For example, Anne argued: ‘...there’s a lot of hours in [organising and facilitating case conferences], to give them [family caregivers] quality information’. She noted that in contrast to current conversations with family caregivers, appropriate and sensitive palliative care case conferencing ‘can’t be done over the phone’. She went on to say: ‘I just thought crikey... we’re not ever going to get through them [15 palliative care planning conferences]...it would end up...a bum rush’. Thus, the group members were prompted to re-consider the feasibility of carrying out the intervention and decided to conduct case conferences with four family caregivers. The group members progressed to Action Cycle 8 where they further revised the implementation strategy.
9.3 Action cycle 8 – Pilot palliative care planning intervention

Figure 28  Action Cycle 8

9.3.1 Replan

The group members made a decision that they would be responsible for piloting the case conferencing intervention given the difficulty they had experienced in getting other staff in the SCU to participate in previous research activities. The RPCP education sessions further affirmed this decision, as group members shared a heightened awareness of the necessity of undertaking preparation with an expert to develop their knowledge and understandings about conducting case conferences.

9.3.1.1 Conceptualising a structured approach

The ARG members consulted the Guidelines (ADoHA 2006) and online ACP resources available on the Palliative Care Australia website (PCA 2005c) prior to planning how the palliative care case conferences would be implemented. Based on their review of these resources the ARG members worked together to develop a structured approach for implementing the intervention. A similar recruitment algorithm to the one used by ARG members in Action Cycle 5 to approach family caregivers\(^\text{10}\), was designed for this intervention (Appendix 31). The algorithm was

\(^{10}\) As previously highlighted by the audit results in Chapter 7 no residents had an enduring guardian (legally appointed decision-maker). Therefore, consistent with facility policy the first nominated contact person in the resident’s file is considered the ‘person responsible’ with whom care processes are discussed and decisions made. Family caregivers involved in this intervention needed to be the first nominated contact person.
approved by HREC, University of Tasmania, for use by the ARG members. This meant that group members would be responsible for approaching family caregivers; introducing the case conferencing intervention to them; and providing them with a participant information sheet. I developed a participant information sheet (see Appendix 32) and consent form (see Appendix 33) which were also approved by the HREC. The ARG members familiarised themselves with these documents prior to distributing them to family caregivers.

On receiving family caregivers’ consent to participate in the intervention, group members planned to provide them with a copy of the POT and the Advance Care Planning Information Sheet. Judy suggested that to avoid family caregivers being ‘bombarded’ with information they should be encouraged to take the document home. This strategy would provide the family caregiver with time to read the information and discuss it with other people who may be important to their decision-making. An appointment would be scheduled approximately 2 weeks after the family caregiver received the information to conduct the case conference.

Group members identified however, that a potential risk to the action would be the difficulty of organising a follow-up meeting with the family caregivers and that this could arrest the continuity of communication and the momentum of the intervention. Therefore, it was agreed that tentative appointments would be made with the family caregiver at the time they were provided with the POT and Advance Care Planning Information Sheet. At the case conference family caregivers would be encouraged to discuss their wishes for their relative’s care and any other related concerns with members of the care team (e.g. RN/EN, PCAs, and GP). During this meeting it was anticipated by the ARG members that the POT would be filled out in collaboration with the family caregivers and signed.

The group members recognised that depending on family caregiver’s individual circumstances more than one case conference may be required and as such this would be dealt with on a case by case basis. A period of 3 months was chosen to trial the case conference intervention. During the group’s deliberations Heather acknowledged that she had struggled to participate in earlier actions due to her clinical supervisory responsibilities and suggested that it may be difficult for her to be involved in this intervention. Therefore, the ARG members decided that Heather could take on the role of a ‘support person’. If for some reason Judy or Anne could
not facilitate a planned case conference, or needed assistance, Heather could be approached to provide backup.

9.3.1.2 Involving GPs

Consistent with the multidisciplinary imperative of care planning, group members were keen to provide opportunities for GPs to be involved in the intervention. Catherine suggested that family members may wish to ‘pay a visit to the doctor’ after having received the information about the intervention. Anne stated that the ARG members could suggest to the family caregiver that in addition to discussing the POT and information sheet with important others, they may also wish to discuss it with their relative’s GP. It was felt that this approach offered ‘flexibility’ to family caregivers if they wished to consult their GP prior to the conference.

The ARG members also decided it was important to explicitly inform GPs of the case conferencing intervention and invite them to participate. Therefore, a letter was drafted (Appendix 34), subsequently approved and sent from the facility manager to GPs of residents. Included with the letter was a copy of the POT form and the Information Sheet. To evaluate the intervention, group members decided to meet 2 months after its commencement to review completed POT forms. They planned to seek feedback from the family caregivers who were involved in the case conferences and document this feedback in their field notes. Final evaluations of these data were planned to occur at the end of the three-month pilot. The group’s plan of action is summarised in Figure 29.
Problem: Current processes for palliative care planning not consistent with best practice standards.

Constitutive Concerns:
- Decision making around care issues associated with the deterioration of a resident’s condition and end-of-life care not proactively discussed with family [Reconnaissance: ARG discussions; Action Cycle 1: narrative accounts of family caregivers, critical dialogues with staff, ARG Collaborative analysis]
- No evidence indicating planned communication processes or meetings between health care team and family caregivers in relation to end-of-life care considerations [Action Cycle 1: Audit findings, criteria 1.6]
- Current facility documentation for end-of-life planning inadequate [Action Cycle: ARG Collaborative analysis]
- Confusion between GPs and nursing staff as to whose role it is to initiate palliative care planning conversations [Action Cycle: critical dialogues with staff, ARG Collaborative analysis]

Strategy for action:
- Pilot palliative care case conferencing with the family caregivers of four residents over a three month period.
- Send invitation letters to GPs.
- Members of the ARG will recruit family caregivers using a method comparable to that outlined in the recruitment algorithm (Appendix 31)
- ARG member to organise case conference date with family caregiver.
- Judy will inform the resident’s GP of the proposed case conference date and other members of the ARG.
- Aim to complete POT in the case conference and/or organise follow-up meetings if necessary.

Monitoring:
- Record research group discussions
- Monitor completion and quality of documentation of POTs
- ARG members to keep field notes

Data sources:
Research group case notes
Completed POTs
Researcher field notes
ARG members’ field notes.

Analysis:
Collaborative thematic analysis with research group of research meeting data.
Qualitative analysis of POT documentation.
Qualitative analysis of ARG field notes.

9.3.1.3 Adopting a pragmatic approach

Judy initiated the final activity undertaken by the group prior to taking action. She organised a meeting with the other ARG members to identify family caregivers who might be potential participants for the intervention. The discussions highlighted the group’s intention to involve family caregivers who they believed would be amenable and responsive to taking part in the pilot. Therefore, family members who were
considered to be ‘disgruntled’ or ‘aggressive’ and thus potentially resistive to the intervention were not considered appropriate for inclusion in the pilot. Group members were also reluctant to involve those family caregivers with whom they did not have an established relationship. For example, Anne argued in the case of a family member who she had ‘only seen...a couple of times’, that to involve him in the research would mean having to ‘start from scratch’ to establish a relationship. This line of discussion also extended to considering which residents’ GPs would agreeable to participating in the intervention. Reflective of the ongoing difficulties encountered in accessing a number of GPs that cared for residents, Judy suggested to the group that they ‘target’ GPs they believed would be willing to participate. At the end of their discussion two GPs and four family caregivers were identified as potential participants.

9.3.2 Take action and collect data

9.3.2.1 Recruiting family caregivers

Judy approached four family caregivers and of these three consented to participate in the intervention. Two of the family caregivers had received an information package, including the booklet about dementia and the SCU fact sheet that were distributed as part of Action Cycle 5. Judy explained that she was able to build on those earlier interactions to highlight the continuity between the research activities and she encouraged them to refer to the information contained in the booklet (pp.23-29) about decision-making for the person with dementia (see Appendix 18 for Information Booklet). The other family caregiver who consented to be part of the intervention, and will be referred to as Len’s daughter, did not participate in Action Cycle 5. Judy suggested that involvement in a palliative care planning case conference ‘may be able to help [Len’s daughter] to make decisions’ about her father’s future care, and provided her with an information sheet for the research and a consent form. To Judy’s surprise within half an hour Len’s daughter had returned the consent form, signed, and indicated an interest in hearing more about the palliative care planning.

The group members met 2 months into the intervention to discuss their progress. Previous to this, three meetings had been scheduled but all were cancelled because group members were unable to attend. At the fourth meeting only Judy (RN) and Anne (EN) were able to participate, during which they reported on the intervention.
9.3.2.2 Three POTs and one case conference: decision to discontinue the intervention

Judy reported that POTs had been completed for three residents. However, only one case conference had occurred during this time because two of the family caregivers had chosen not to participate in a case conference. During this meeting Anne also shared accounts of feeling exhausted by her attempts to integrate research activities with her work demands. Judy explained that she was feeling ‘quite frustrated’ in her efforts to implement the intervention amidst increasing pressure of staffing issues and workloads. She argued that conditions in the unit had inhibited the ARG members from participating in the action ‘as a team’, explaining that Catherine and Elizabeth had not had an opportunity to take part in the action. Likewise, Anne explained that she had ‘struggled’ to contribute to the intervention leaving Judy with this task. Reflecting on these circumstances Anne suggested that the intervention ‘was getting to a stage’ where the inability of group members to meaningfully engage meant that continuing with the pilot was unsustainable. In response Judy suggested that the pilot be discontinued. This decision was taken to the next ARG meeting and received the support of the other ARG members.

9.3.3 Analysis

An analysis of the three de-identified POTs revealed that:

- All family caregivers indicated that they were the ‘person responsible’ to make medical decisions on behalf of the person with dementia.
- Two POTs had “Palliative Care 1” as the chosen level of care.
- One POT had “Palliative Care 1” chosen with additional information about the trial of medications.

Both of the family caregivers who completed the POT forms but chose not to participate in a case conference returned the completed documents to Judy. She stated that both family caregivers were ‘very fixed’ on what they wanted for their relative’s care and as such she reported that she did not pursue any further discussion with them about what they had written in the POT.

Len’s daughter was the only family member to be involved in a case conference. Judy reported in her field notes: ‘...the conference lasted for about one and a quarter hours ...[Dr Jacobs] gave a lot of...case scenarios’. An analysis of Len’s POT found that “Palliative 1” and “Palliative 2” levels of care had been chosen by his daughter.
These results were somewhat confusing as “Palliative 1” was chiefly concerned with supportive care measures, while “Palliative Care 2” included somewhat more active care including hospital transfer and some actions to treat illness. By choosing both levels of care, more specific requests made by Len’s daughter were not clear. For example, on the POT it was indicated that if Len’s condition deteriorated and death was a likely possibility that he was ‘not be transferred to hospital unless absolutely necessary...only be given interventions to improve comfort... be provided with measures at the facility to enhance comfort’. However, in the next section of the form Len’s daughter also requested that her father ‘be provided with interventions (e.g. blood tests, transfusions, IV/SC fluids) and a trial of drugs (e.g. antibiotics) as deemed medically appropriate to either improve comfort of the resident’s condition’.

On describing these data Judy explained that choosing both levels of care meant that if Len deteriorated overnight and ‘Dr Jacobs wouldn’t get here [to the facility] because it was two o’clock in the morning...[Len] would be sent off [to hospital]’. However, when Judy considered whether these wishes were in fact Len’s daughter and not just those of the GP, she seemed uncertain and stated: ‘I don’t know, I mean you’d have to be doing something wouldn’t you?’ In an attempt to clarify the intent of the documentation on Len’s POT, Anne stated:

...what I understand...[Len’s daughter is] saying is I want him in the facility if he is dying, I don’t want him transferred around, but I do want some sort of treatment if it’s going to help him, so for a chest infection I want him to have antibiotics. She’s basically saying I want him kept comfortable...

While agreeing with Anne’s suggestion Judy stated that decisions about future care were ‘grey areas!’ and that she would not feel comfortable to elicit further detail from Len’s daughter.

9.3.4 Reflection

9.3.4.1 Recognising the complexity of palliative care planning

Immediately evident in ARG members’ reflections was their increased recognition of palliative care planning as a complex task. Judy recalled that she and Len’s GP ‘really struggled’ when discussing the POT with Len’s daughter. On further consideration of this experience, Judy explained that the challenge to communicating about issues of deterioration and dying was what she described as the ‘grey areas’.
To further make her point she highlighted that in the absence of a clearly-defined course of deterioration for people with dementia, palliative care planning discussions were ‘not black and white’. Rather, Judy asserted that there was an inherent level of uncertainty and ambiguity about future events, which had resulted in her feeling ‘not comfortable’ to discuss family members’ wishes in more detail beyond what they had specified on the POT. Hence, her cursory conversations with those family members who chose not to participate in a case conference. However, when reflecting on her limited interactions, Judy recognised that in contrast, the case conference with Len’s daughter had been a supportive and interactive experience. In response to Judy’s accounts, Anne suggested that ARG members would ‘need more education’ and ‘more support’ to confidently and effectively implement palliative care planning processes in the SCU. These reflections illustrate that members had developed greater insights not only about the complexity of palliative care planning but their own capabilities.

9.3.4.2 Benefits of case conferencing: opening up possibilities for dialogue

Despite only one case conference being conducted, group members considered that the intervention still demonstrated positive outcomes. For example, Judy reported that Len’s daughter benefited from the discussions that took place stating:

She [Len’s daughter] got a lot out of it. I know she did because she came back to me yesterday and said “it was really good”, she felt very supported…she said “Dr Jacobs didn’t rush…[I] found him so easy to converse with… I found it very, very good.

Judy claimed that as a result of the intervention Len’s daughter’s responses had ‘turned around’, so that she was more relaxed when discussing her father’s health problems. Anne argued that initiating a case conference with Len’s daughter was a significant achievement, because in her opinion, Len’s daughter would have been unlikely to initiate such discussions herself. Anne stated: ‘I don’t think…she [Len’s Daughter] would talk about any problems, she would just fester with them’. Reflecting on the case conference, Anne and Judy both contended that opening a dialogue about sensitive issues with Len’s daughter had assisted her ‘to feel comfortable’ to raise questions and be ‘reassured’ that she was supported by staff to do so.
9.3.4.3 Factors constraining action: ‘going in at the deep end’

At a meeting where all of the ARG members were present their accounts highlighted the tensions between their workloads and the implementation of the intervention. For example, Judy explained that trying to implement case conferencing in addition to undertaking her clinical duties had compounded ‘the stress’ of her ‘full on’ working day. Likewise, Anne explained that having contact with family members in the SCU was a ‘struggle’. Catherine and Elizabeth also had limited ability to participate in the intervention. Catherine stated, ‘it’s just such a full on unit up there [SCU]...you just don’t have much time at all’. Moreover, the case conference with Len’s daughter had been scheduled to occur in the morning so that the GP could attend. However, this meant that Catherine and Elizabeth were unable to participate as they could not leave or defer care tasks for residents who were dependent on their assistance.

When reflecting on the group’s efforts to implement the intervention strategy Judy argued that without the active support of management so that staff members could take time away from their duties, the likelihood of conducting case conferencing in the unit was slim. She asserted: ‘there is not support behind you...[and] you go in the deep end!’ Indeed it was at this point that Judy explained that she had had to leave the case conference with Len’s daughter and the GP prior to its completion because, as she stated ‘it [the meeting] was 12 o’clock, I had to go and get [resident] medications’. Anne also shared concerns about the ability of staff on the SCU to implement palliative care case conferencing under the existing workplace conditions. She stated, ‘you really would have to get people to do it [case-conferencing] when they are not working’. On the whole, group members recognised that they required much greater resourcing to successfully implement case conferencing as an integrated part of their practice in the unit. Judy reflected that in hindsight the group members needed to engage management support more actively to ensure that appropriate resources could be provided.

9.3.4.4 Group member fatigue

In their final reflections on the action, group members suggested a sense of relief that the intervention had drawn to an end. At this point in the project it was evident that group members were fatigued by their engagement in the research. For example, Anne explained being ‘pleased’ that the palliative care planning intervention was ‘over with’ recalling that she had felt under ‘pressure’ to try and complete her usual
work as well as the research activities. As such, Anne reported being troubled by feelings that she ‘hadn’t contributed’ at points during the research when she was unable to negotiate her participation with existing work demands. In recognition of the complexity of demands on staff members’ energies and time Judy asserted that ‘you just can’t stretch yourself’. These reflections provided compelling insights not only into the capacity of staff to execute changes in their practice but also their ability to support a research agenda for a sustained period of time. This tension was no more evident than when Anne voiced relief that the project was in its final stage stating ‘…really [I’m]…just stretching myself to a point where I’m over it [the research]’.

9.4 Discussion

While the ARG did not achieve their planned outcomes for their last two intervention strategies, their reflections on taking action provided critical insights about the barriers to implementing best practice to support a palliative approach to care. This discussion builds on a number of key issues that have been explicated in Chapter 8, namely, the operation of hegemonic power relations in the SCU and the influence of other material (e.g. resourcing) and cultural conditions on the capacity of staff to implement change that was predicated on a collaborative ethic.

The ARG’s analyses of their attempts to pilot the PAM strategy confirmed the importance of these staff having the opportunity to interrogate competing interests that shaped their practices. The initial reflections of the group suggested that a lack of participation by SCU staff was due to a general reluctance to change. However, as their stories unfolded the group members were able to more accurately “give voice to the complexity” (Aranda & Street 2001, p.797) of the circumstances initially taken-for-granted in practice. Reflective of their shifting narratives, the ARG came to recognise that their colleagues were not knowingly resistant to change. Rather, they shared new insights into the hegemonic interests that bounded the actions of staff and hence their capacity to engage in a collaborative endeavour such as the PAM strategy.

Not surprisingly, resourcing issues were prominent factors identified as limiting the extent of change that could be achieved. Consistent with recent research by McConingley and colleagues (2008), the findings of this study highlight that limited availability of time and personnel to engage in best practice pain management
activities are key barriers to change. The reflections of the ARG group members also confirmed that extra documentation associated with best practice was perceived to be an additional burden, a finding also reported by McConigley et al (2008) as a deterrent to implementation. Therefore, this study suggests RACF staff struggle to implement innovation in a system that as Chenoweth and Kilstoff (2002, p.237) have described “…is directed towards outcomes of care” and linked to regulation and funding, rather than “inputs to care provision such as staffing and infrastructure costs”. For staff enmeshed in these conditions it was apparent that the burden of any added paperwork overshadowed the potential value of best practice pain management. The task of assessing symptoms such as pain, particularly in residents who are unable to verbalise their discomfort, has been described in the literature as compounding the complexity of care provision (Wowchuk et al. 2006). This was confirmed by one of the ARG members who described pain assessments as a type of ‘detective work’ that presented a further impost on their time. Arguably, the PAM strategy also presented an additional set of challenges to already stressed staff whose response, in the context of socio-political conditions, discussed next, can be understood as similar to what Chenoweth and Kilstoff (2002, p.238) have described as “resistance and retreat”.

As the group’s analyses unfolded they progressively interrogated the socio-political interests that constrained the implementation of the PAM strategy. The critical reflections of the group revealed that the operation of hierarchical power relations between PCAs and nursing staff, in the SCU, undermined the collaborative ethic of the intervention. Their narratives illustrated what Lindeman et al. (2003, p.29) have described as “strong occupational-based authority structures” that demarcate staff roles. According to Street (1992, p.39), these types of hegemonic relations maintain the “status quo” that legitimates one group’s knowledge (such as nursing staff) as superior over another (such as PCAs). With respect to the aged care environment Jervis (2002) has argued that nursing assistants (equivalent to PCAs) are at the bottom of the “chain of command”. He (Jervis 2001, p.89) suggests that task delineation within organisational hierarchy is important in “solidifying the boundaries between differently ranked categories of people”. Maintaining these boundaries is arguably reflective of the ideological imperatives of an aged care sector geared towards so called “efficiency”, meaning employing a cheaper workforce. Indeed, one of the most influential reviews in the history of aged care (Hogan 2004) made explicit that the increases in unregulated, supervised practitioners (PCAs) was
one of the workforce changes that reflected “more efficient workforce structures” (p.221). Yet embedded within these supposedly more efficient structures, entrenched hierarchies confound the possibilities for PCAs to expand their roles in ways that could support the delivery of a palliative approach to care.

Problems inherent in hierarchical staffing structures were further highlighted when PCAs in the SCU refused to participate in piloting the PAM strategy. According to the ARG members, this action was taken in retaliation to a delay in being paid for attending an education session in Action Cycle 4. Jervis (2002, 2001) provides one way of understanding this finding when he reported that nursing assistants in UK nursing homes engaged in forms of low profile resistance as a means of challenging what they considered to be conditions of subjugation by more senior staff. Similarly, the contestation of power by PCAs, evident in their refusal to participate in Action Cycle 6, can be understood as a response to what they perceived as unjust conditions, which Chenoweth and Kilstoff have described (2002, p.240) as being situated “outside their own locus of control”.

While reflections of the ARG members during Action Cycles 4 and 5 raised staff hierarchy as an issue, these discussions occurred in the context of successful interventions. As such, members’ reflections were largely focused around the benefits of them having worked in partnership. It was not until members were confronted with the emerging reality of a failed intervention strategy that the insidious workings of dominant power relations were more widely exposed. Phillips et al. (2008) have reported similar findings when attempting to implement a palliative approach to care in a number of RACFs. It was reported that when PCAs in the project demonstrated enhanced palliative care competencies and an improved ability to communicate their clinical observations, some nursing staff did not respond favourably to the “status quo” being disrupted (Phillips et al. 2008, p.221).

Having engaged in extensive discussions about the PAM strategy, the group members questioned the extent to which change could be affected in the SCU under conditions that did not provide opportunities for collaborative working. As a result, when they progressed to Action Cycle 7, they planned the palliative care case conferencing intervention so that they would be solely responsible for it. This decision was informed by the group’s heightened awareness that the power relations in the SCU undermined collaboration between staff who were not members of the ARG. There was a new appreciation amongst the ARG members about the role of
PCAs in palliative care planning processes following their involvement in the RPCP (2007) education sessions. Both Catherine and Elizabeth envisaged greater possibilities for their roles in the case conferences. Previous research (Dowding & Homer 2000; Ersek et al. 1999) has reported that PCAs are not routinely consulted as members of the care team who can make valuable contributions to care and care planning. However, the findings of this study suggest that through accessing expert information networks and having opportunities to critically reflect on their role, the PCAs and the other group members embraced a collaborative orientation for action.

Reflective of the ARG members’ sense of ownership over the research process, the decision was made to reduce the number of case conferences to be piloted from 15 to 4. They also resolved to only conduct pilots with family caregivers whom they considered would be responsive to the intervention. These decisions illustrated the group members’ skills as researchers. Additionally, the group’s acknowledgement part way through the palliative care planning intervention that their participation had been overwhelmed by competing workplace demands was further demonstrative of an awareness of their own limitations to affect change. Resourcing issues, unrelenting staff shortages and heavy workloads have been previously articulated in the literature as impacting on the capacity of RACF staff to engage in ACP and end-of-life planning discussions (Froggatt et al. 2008; Lyon 2007). Indeed, it was evident from the reflections of ARG members that they had little reserve capacity to implement the intervention. This finding resonates with those of Robinson, Andrews and Fassett (2007) who have identified that aged care staff struggle to create an environment supportive of best practice when there are unstable institutional conditions. With the PCAs in the ARG being responsible for the care of between 9 and 12 residents on any given day, it is understandable that their ability to leave their care duties to participate in case conferences was significantly compromised, as these were conditions that they had little control over.

The reflections of ARG members that highlighted their needs for more support, confirmed that they were not adequately resourced to implement case conferencing on the unit. During their planning discussions, members had anticipated a lack of time and availability as potential risks to the intervention. However, it was not until they attempted to take action that they were confronted with the full extent of their inability to operationalise a case conferencing process, that has been promoted as a central aspect of a palliative approach to care (ADoHA 2006). The group members
identified an imperative to seek greater management support to facilitate the implementation of this type of intervention. With enhanced support the group members suggested that barriers such as workloads and availability of staff be effectively negotiated. Lyons (2007) has demonstrated that implementing an ACP process in a RACF requires the active engagement of senior management so that staff members feel supported and valued through their participation in processes to improve their practice. Likewise, recent research by Froggatt (2009) has suggested managers in long term care settings taking a leadership role to support ACP processes, however she raises concerns about their confidence and expertise to do this. The reflections of the ARG members demonstrated their new found insights into the complexities of conducting palliative care planning care conferences.

In addition to resourcing issues, the findings also indicated that socio-cultural understandings about death, dying and dementia were a barrier to ARG members operationalising the palliative care planning case conferences. References by those staff members, who were clinical leaders in the SCU, to discussions with family members about palliative care planning as comprising ‘grey areas’ suggested that despite their preparatory activities, dementia and dying continued to be ambiguous topics which they felt unprepared to address. For the ARG members and arguably the GP involved in the one case conference that did occur, the dying trajectory of people with dementia was not be easily identified. While studies have suggested that family caregivers of people with severe dementia struggle to recognise the dying trajectory (Forbes et al. 2000), the findings of this study suggest that health professionals also experience a similar conundrum. Kellehear (2001, p.510) has suggested that “the prevailing view of dying as a physical problem” not only supports notions of medical dominance over death, but more problematically, it fails to recognise the needs of those people (family members, people with dementia) “living with dying”. Indeed Judy’s reflections about accepting completed POTs from two family caregivers and pursuing little discussion about their wishes suggests consistency with the literature (O’Connor 2004; O’Connor 2009; Komaromy 2000) that issues of dying continue to be excluded from institutional and care related discourse. These conditions present significant challenges to the development of practices of aged care staff around a palliative approach.

Finally, ARG members’ reflections on their fatigue associated with their engagement in the research process illustrated the ‘real-life’ effects that can be associated with the
conduct of participatory research. After 21 months of field work in a setting that was resource-stretched and subject to a range of competing socio-political interests, the capacity of the ARG members to sustain their involvement in the research had been vastly reduced. Members were exhausted by meeting the extra demands of the research in the context of competing care and institutional priorities. Therefore, the decision to discontinue the case conferencing pilot seemed to be the most appropriate available to the group and to me as the researcher. These findings highlight the potential for an action-oriented research agenda to become a burden on participants, as has been highlighted by others (Koch & Crichton 2007). Therefore, the importance of having established collaborative, reciprocal relations with the ARG members cannot be overstated, as the decision to withdraw from research activities was largely facilitated by their willingness and openness to share with me that they lacked the energy to continue. Therefore, while the ARG members took critically-informed action with the best of intentions to support evidence-based pain management and palliative care planning processes, organisational and socio-political conditions thwarted their attempts to engage in these collaborative intervention strategies. Wider changes in the practices, understandings and relationships of staff members would be difficult to achieve without pre-existing conditions in the SCU that would support collaborative enterprises. The findings of this study suggest a need for a re-examination of material, social and cultural conditions in RACFs. It supports the perspectives (Froggatt 2000a; Froggatt 2000b; Phillips et al. 2008) that the complexity of aged care settings necessitates more than education alone to achieve wider practice and cultural change in order to support the delivery of a palliative approach to care for people with dementia.

To conclude this chapter, I return to the second research sub-question posed in this study: What are the factors/conditions that constrain aged care staff from delivering an evidence-based palliative approach to care on the SCU?

I have chosen to address this research question here, rather than earlier in the study, because as evident in the findings of the later action cycles, the group members needed to go back to practice and take action, in order to uncover some of the more deeply embedded and previously unrecognised conditions that constrained their ability to support a palliative approach. Therefore, drawing on findings from the reconnaissance through to the final action cycle it is apparent that a range of complex contextual factors have emerged.
Firstly, and most evident to the ARG members was that inadequate resourcing, short staffing and skill mix profoundly shaped how care was provided. The ARG members’ narratives suggest that RACF staff practice within a relentless churn of conditions that predominantly support economic-rationalist agendas of providers and regulatory requirements of the sector. It was apparent that heavy workloads overwhelmed their capacity to identify possibilities for practicing differently, while seemingly perfunctory documentation that met regulatory requirements had little validity to improving resident care or information provision to family caregivers. Additionally, high resident to staff ratios meant that care practices were focused on institutional rather than person or family-centred needs. The incessant administrative/managerial demands placed on nursing staff and their relative isolation from other colleagues within the sector (GPs, other RNs, specialist services) limited their capacity for “creative and skilful care” (Venturato et al. 2006, pp.332-3). Likewise, the PCAs in the ARG highlighted the inevitability of their practices being constructed around physical care tasks. This study found that the culture of care in the SCU was predominantly focused on compliance and ritualism. The privileging of “instrumental” care practices in RACFs has been highlighted by others (Bowers et al. 2001; Tuckett 2005), at the relative neglect of a person-centred culture of care (Kitwood 1997). Moreover, opportunities for the development of “interpersonal” and “reciprocal” relationships with family caregivers, that according to recent research (Brown Wilson et al. 2009) improves the experience and quality of care were undermined in the study setting by care practices being understood and constructed in technical and reactive ways.

The findings suggest that staff in this study were faced with practicing in a nexus, where dominant institutional interests that shaped their practices failed to recognise the complexity of caring for people with advanced dementia, while at the same time the responsibility and accountability for holistic care was placed on over-stretched and often ill-prepared staff. Hence, without proactive engagement from management and a recognition of the imperative to support staff so that they may be able to reconfigure their practices to better support a palliative approach to care, staff will struggle to envisage change within the inertia of everyday practice.

In addition to the above circumstances, competing socio-political interests of different groups within the RACF undermined opportunities for staff members to engage with evidence that could inform their practices and allow for collaboration.
between staff members and with family caregivers. Hegemonic power relations were exposed at the level of “micro-practices” (Foucault 1972) of aged care staff. For example, with management being responsible for disseminating evidence to staff members in the SCU, and a situation in which staff themselves were complicit, this hierarchical distribution of knowledge meant that staff did not pursue more proactive means of accessing evidence that could inform their palliative care practices. While issues of staff hierarchy on communication processes and information sharing have been scattered throughout literature (McDonnell et al. 2009; Whittaker et al. 2007; Wilson & Daley 1998; Dowding & Homer 2000), this study brings into focus the pervasive nature of hierarchical power relations on the capacity of staff to support a palliative approach to care.

Finally, cultural conditions on the SCU were also found to sit in tension with the goal of a palliative approach to foster “an open approach to discussion of death and dying between the aged care team, resident and their families” (ADoHA 2006, p.4). Consistent with cultural imperatives of “healthy ageing” (O'Connor 2009; Abbey 1994; Abbey et al. 2006), the SCU staff privileged a restorative/rehabilitative focus of care. However, this culture sits in tension with the reality of RACFs as sites that provide care for increasingly dependent, older people (Andrews-Hall et al. 2007). The broader cultural unacceptability and unpalatability of death also deterred aged care staff from talking with family members about dying, a topic they found to be personally uncomfortable. Moreover, consistent with the findings of Godwin and Walter (2009) the unpredictability of decline associated with the dementia trajectory hindered much needed discussion with families about deterioration and dying.

Given the complexity of factors that constrain the capacity of RACF staff to deliver a palliative approach to care, the final chapter of this thesis addresses strategies emerging from this study that have opened up possibilities for change and improvement.
Chapter 10: Conclusions and Reflections

This thesis has chronicled the journey of members of an action research group working in a dementia SCU, as they engaged in a critical action research process. In this final chapter I will address the last sub-question posed in Chapter 1, which asked, *What strategies will enable/support aged care staff to develop their practices around palliative approach to care?* To answer this question I will draw on the final reflections of the ARG members about the changes that occurred in their understandings, practices and relationships as a consequence of their participation in this study. These reflections, in addition to other key findings, support the use of strategies that engage aged care staff in critical, collaborative endeavours to develop their practices around a palliative approach to care. Recommendations for future action and research that could contribute to the development of a context conducive to collaborative approaches and innovation in RACFs are discussed. The chapter concludes with my reflections on the research process.

10.1 Strategies to support aged care staff to develop their practices around a palliative approach to care

In Chapter 3 (Table 1, p. 70) a framework for monitoring change was proposed. Key changes in understandings, practices and relationships were then mapped throughout the course of the project and have been highlighted in the preceding chapters. Within this section changes that emerged following the completion of the group members’ intervention activities are documented. In addition to revealing these changes, the group members’ final reflections also provide evidence that support the imperative for collaboration, the democratization of knowledge and opportunities to take critically informed action.

10.1.1 Setting up conditions for collaboration

In this study, strategies and processes positioned within a critical action research method were essential in supporting aged care staff members to develop their practices around a palliative approach to care. Prior to the study, the SCU staff that formed the ARG had never been approached to work together in a process that aimed to improve the provision of care for people with dementia. This is perhaps not surprising given the monolithic cultural conditions of the aged care setting, exposed
through the findings of this study that constrain the capacity of staff to collaboratively and critically explore their practices. Setting up conditions for collaboration and the democratisation of knowledge production was crucial to creating opportunities for the ARG members to describe their practices “as concretely and precisely as possible in particular material, social and historical circumstances” (Kemmis & Wilkinson 1998, p.25) and through this process recognise possibilities for change.

The importance of establishing conditions that promoted collaboration between the ARG members became evident early in the study. The Reconnaissance revealed that dominant interests, focused on efficiency and economic imperatives, shaped the practices of staff members. Reflective of these circumstances and in support of concerns raised in the literature (Avis et al. 1999; Jones et al. 2002; Jervis 2002), the findings of this study highlighted that the ARG members practiced in relative isolation from one another. Having no prior experience of participating in a collaborative research endeavour, a key strategy to support the ARG members was to provide them with opportunities to share their knowledge and experiences from practice. The process of bringing these staff together occurred through what I described previously as a “facilitated engagement”.

In my role as a facilitator I provided opportunities for the ARG members to meet regularly and share their stories, which in turn opened what Habermas (1996) has referred to as a “communicative space”. By telling stories, group members recognised their shared concerns, which provided them with an impetus to seek mutual understandings of their situation. I stimulated the group to critically reflect on their emerging narratives; and consistent with the perspectives of Koch and Kralick (2006, p.29) the group members progressively created a space for talking about issues that were previously silenced. Wadsworth (2001, p.322) has recognised that opening a dialogic space where people can “share” in a process of inquiry about their practices is crucial to success in action research projects. One of the ARG members Anne, reflected on the importance of the facilitated engagement in the project and she stated: ‘we needed something to bring us together’. In accordance with the framework for monitoring change outlined in Chapter 3 (Table 1, p. 70), the group members’ recognition of the importance of engaging in a shared inquiry was reflective of their changed understandings about the value of participating in an action research project. Anne stated that having regular, scheduled meetings as part
of the research process was ‘excellent’. She explained that ‘getting together and raising issues’ had enabled the group members to explore a diversity of concerns.

Having opportunities to meet regularly and share stories enabled the development of collaborative, dialogic relations between the group members. For these staff, strategies that fostered democratic forms of discussion promoted the development of a sense of solidarity and a collective desire to explore ways to develop their practices around a palliative approach to care. While mindful of cautions made within the action research literature about the potential for the emergence of a “rhetoric of democracy” (Reason 2003, p.110), the reflections of the ARG members at the completion of the study were suggestive of a more egalitarian sharing of ideas. This marked another important change in relationships between the group members, as was previously set out in the framework for monitoring change (Chapter 3, Table1).

For example Catherine, a PCA, reflected in the final research meeting that she felt her contribution of ideas to the group’s discussions were ‘more valued’. Elizabeth, also a PCA, felt her opinions were ‘respected’ by other members of the ARG. For these two staff members, having their perspectives listened to and being able to actively shape the group’s understandings about providing a palliative approach to care in the SCU, reflected a shift in their historical positioning as subordinate to nursing’s “expert” knowledge. Within the literature, PCAs have been reported to have the least autonomy in the “heirarchicalized” (Jervis 2002 p.16) approach to care in aged care settings, despite having the highest level of accessibility to residents and their families. Historically, PCAs have been silenced by the operation of dominant power relations that deny the legitimacy of their concerns within the care setting (Jervis 2002, 2001). Reflecting Foucault’s (1977b) conception of the inextricable relationship between power and knowledge, the findings of this study suggest that collaborative dialogue is a key strategy to promote a reconfiguration of hierarchical power relations between aged care staff members. Given that a palliative approach to care is underpinned by a principal ethos of teamwork and multidisciplinary collaboration (ADoHA 2006), the significance of building partnerships between nursing and care staff cannot be overstated.

Demonstrative of changed relationships between the ARG members, Judy suggested that as a result of her participation in the study she was ‘less strict’ when working with the PCAs from the research group. She argued that this change reflected her deeper appreciation of the need to be ‘adaptable’ and work across previously
demarcated role boundaries to deliver care for residents and their family caregivers that was consistent with a palliative approach. Similarly, Catherine explained that she valued working as part of a ‘strong team’ where her capabilities to provide more holistic care were acknowledged and respected. These changes in the understandings of and relationships between the group members were illustrative of them having developed what Freidman (2001, pp.132-133) has described as “a community of inquiry within a community of practice”. The development of such a community in this study was a crucial strategy to reconfiguring the power relations between group members, which in turn enabled them to develop new understandings and practices that supported a palliative approach to care on the SCU.

Rudolph, Taylor and Foldy (2001, p.308) have argued that by people “working with others” to penetrate “established patterns of seeing and acting that are often invisible”, a greater appreciation of the gaps between one’s espoused theories and actual practice can be achieved. In support of this perspective, Heather reflected during the last ARG meeting on the importance of ‘opportunities to talk’ with others, stating that it was ‘essential...to find out exactly what was going on [in practice]’. The findings of this study illustrate that if aged staff are to develop a greater awareness of the “common sense” (Gramsci 1971, p.420) assumptions and hegemonic power relations that constrain their capacity to support a palliative approach to care, it is imperative to have a safe space where they can talk and develop reciprocal relationships.

10.1.2 Democratisation of knowledge

The reciprocity engendered in sharing all of the research data with the ARG members provoked, as Greenwood and Levin (1998, p.96) have suggested, “a constant dialogue between the possible and the actual” for the ARG members. During this process, I progressively adopted the role of a “critical companion” (McCormack et al. 1999, p.260), who accompanied the ARG members in generating critically reflective knowledge about their practice and recognising opportunities for change. The group members embraced their roles as “practitioner researchers” (Dewing & Traynor 2005, p.701) responsible for interrogating their practices, ideas and assumptions about the provision of palliative care to residents in the SCU. In the final ARG meeting, group members’ reflections demonstrated an important change in their practices, being that they had developed a more critical orientation to how they provided care on the SCU. For example, Catherine explained that as a result of
her participation as a co-researcher in this study: ‘I work with more insight now’. Similarly, Anne suggested a critical orientation to her practice when she explained: ‘I think differently about work...about what I’m doing’.

With their evolving critical engagement throughout the study, the ARG members developed a greater awareness of their complicity in unwittingly supporting the dominant interests of others, which undermined their capacity to deliver a palliative approach to care. This change in understanding was evident when group members identified how their historic privileging of regulatory and institutional interests, contributed to reactive care practices and perfunctory care-related documentation. Arguably, such hegemonic circumstances arise and are sustained by what Foucault (1978) has described as processes of self-subjection or self-regulation, whereby people such as aged care staff members internalise the values and goals of “an external authority”, which become the organising principles for their practices (Rainbow 1991, p.11). Indeed, the findings of this study highlight that the core business of the RACF was not geared towards the delivery of a palliative approach to care for residents. Judy expressed this understanding when she reflected in the final ARG meeting on how communication between staff and with residents and their family members was ‘functional’. She reflected that care practices were ‘process focused’ rather than being ‘people focused’ and that while privileging administrative processes ‘kept the validators happy’, Judy was adamant that such an orientation to care failed to meet the needs of residents and their family members.

Importantly, the engagement of the ARG members as “co-researchers” and “active agents” (Heron & Reason 2001, pp.144-145) in the construction of knowledge, provided opportunities for them to expose the hegemony of institutional interests. In many respects this shifted the boundaries of what was “knowledgeable” and thus what was possible (Gaventa & Cornwell 2001, p.74) for the ARG members as they explored ways to develop their practices around a palliative approach to care. Through what Habermas (1984, p.268) has referred to as “communicative action”, group members planned strategic action that challenged their habitual ways of practicing. Thus through their critical engagement the ARG members sought to shape their care practices in response to the identified needs of SCU staff, residents and family members with respect to a palliative approach framework. In her final reflections, Heather suggested that planning action ‘towards... the same goal [a
palliative approach to care]’ was an empowering process as she stated: ‘it’s the belief that you can be doing something that you didn’t think was...possible before’.

10.1.3 The importance of taking action

In addition to strategies that fostered critical, collaborative dialogic engagement between the ARG members, another important strategy that enabled the members to develop their practices around a palliative approach to care was the opportunity to take informed action.

Firstly, taking action to develop the SCU staff education sessions and information packages for family members, required the ARG to have a radically different engagement in their practice. Consistent with the framework for monitoring change (see Table 1, p.70) the ARG members demonstrated changes in their practices to better reflect best practice standards for a palliative approach. Constructing and implementing evidence-based interventions, challenged the habitual ways of working. For example, Anne reflected that she was capable of ‘doing] more’ than ‘just giving out drugs’. Similarly, Catherine, one of the PCAs in the group recounted that taking action had ‘broadened [her] horizons’. As a result, she had recognised that embedded within her everyday practice was expertise which she could draw on to support the delivery of a palliative approach to care for SCU residents. Elizabeth, also a PCA, suggested that having opportunities to engage in informed action had ‘opened’ a deeper awareness about how aspects of her practice were ‘not quite so normal’ as she had once thought. She highlighted a new appreciation for her intimate knowledge of residents and needs of family members that had been revealed during the study. These reflections highlight an empowering feature of taking action to change practice, suggesting that it can create possibilities for what Foucault (1977b, p.82) has referred to as “insurrection of subjugated knowledges”, which have previously been “disqualified as inadequate...naive knowledges located low down the hierarchy”. Taken from this perspective, the development of “knowledge-in-action” (Reason & Bradbury 2001c, p.2) has transformative possibilities, by recovering non-dominant and “tacit knowledge” (Rycroft-Malone et al. 2002, p.175) of aged care staff that can facilitate more holistic care provision. In this study, giving voice to subjugated and tacit knowledges, through reflection-on-action, had positive implications for the reconstruction of care practices that better supported a palliative approach.
In their final reflections, it was evident that the group members shared a greater
appreciation of collaborative action as a strategy to reduce their previously felt
isolation on the SCU and support the development of a culture that embraced a
partnership ethos. Working in partnership to provide information packages to family
caregivers was, according to Judy, ‘the most positive outcome [of the study]’. It also
represented a significant change in the practices of group members, who prior to the
study had highly demarcated roles. The group members’ efforts to work in
partnership and at times “blur” role boundaries reflected an albeit small but
significant “transformative cultural shift” (Robinson 1995). Moreover, this shift in
turn opened up possibilities to challenge historically hierarchical relationships with
family caregivers. When reflecting on their action to provide family caregivers with
information packages, changes in the language used by the ARG members suggested
enhanced perceptions of family caregivers as legitimate members of the care unit.
For example, group members referred to their interactions with family members
through language such as “talking with” and “spending time with” and being ‘more
involved’. Arguably, by the group members taking action, the “productive” features
(Foucault 1977b, p.119) of power relations were harnessed towards more equitable
outcomes with families.

The importance of being able to interrogate practice in the context of taking action
was further evident when, in their attempts to bring about change, the ARG members
were confronted by competing interests that had remained largely taken-for-granted
through their earlier critical inquiry. Indeed Kurt Lewin’s (cited in Koch & Kralik
2006, p.12) well known maxim – “if you truly want to understand something then try
to change it” – strongly resonates with some of the findings of this project. The
importance of having management actively engaged in the research agenda became
apparent as the ARG members reflected on their difficulty in getting staff to attend
education sessions and their finding time to pilot the pain management and palliative
care planning action plans. In contrast to their limited dialogue about the role of
management early on in the project, the group members’ final reflections suggested a
greater awareness of how management staff, by virtue of their position, could
facilitate or undermine the progress of a change agenda. Judy reflected that ‘there
needed to be more management support’ for the project. In response, Heather
suggested that ‘communicating with [the DON] every now and then’ in addition to
the steering committee meetings ‘wasn’t enough’. Indeed, the highly political nature
of a “bottom-up” change agenda had become increasingly evident to the group
members. Reflective of this changed understanding, Anne recognised a need to ‘do things differently’ in the future, which Judy subsequently described as the need for ‘better connections’ between the ARG and facility management. The reflections of the ARG members suggest a recognition of their responsibility to devise strategies to engage management more deeply in a change agenda; and thereby drive cultural change at a macro-political level to support the development of a palliative approach to care.

Finally, the effects of hierarchical power relations between SCU staff were further revealed to the group in taking action to pilot the PAM strategy. Indeed, the ARG members were so embedded within the institutional hierarchy of the setting that they struggled to recognise this construct as a potentially limiting factor to change during their planning activities. In a similar manner, the pilot of the palliative care case conferencing intervention also illustrated the resistance of habit and commonsense, or what Robinson (2001, p.65) has described as “hegemonic technologies”, that supported a death-averse culture on the SCU. Foucault (1977a, p.156) might have described this situation as the “diabolical” aspect of power, in that it is a “machine in which everyone is caught”, including the ARG members. The elusiveness of institutional hegemony meant that, despite their emerging sense of empowerment, as the ARG members imagined possibilities for change and improvement, they simultaneously struggled to acknowledge the “normalising”, “self-monitoring” (Riley & Manias 2002, p.263) processes to which they and other staff unwittingly ascribed. In their final reflections, the ARG members shared new insights about the limited capacity of SCU staff to achieve change towards improving their palliative care practices, when trapped in the network of power relations seemingly invisible within “everyday” practice. In recognition of this issue, Judy argued, ‘...it’s beyond the staff outside the research group, to [change] practice’. Arguably, this realisation, while not directly expressed as praxis, reflected a new understanding amongst the group that the development of a palliative approach to care relies on strategies that engage staff in critical, reflexive dialogue and informed action.

### 10.2 Recommendations for future research

#### 10.2.1 Understanding complexity and adopting participatory approaches

It is evident from the findings of this study that aged care staff practice in a highly contested and complex space where care provision is driven by technical-managerial
agendas. In her writings on knowledge translation and organisational change, Kitson (2008, p.218) proposes that researchers and practitioners need to share a greater awareness of health care systems as “complex, interactive [and] organic”. She argues that this shift is a philosophical one as it requires that the traditional conceptualisation of health care systems based in predominately “mechanical and technical” perspectives be more holistic. To achieve this, the findings of this study indicate that there is an imperative to further explicate the interconnections of economic and socio-cultural interests in aged care settings that privilege reactive, task-oriented, heirarchicalised care provision for people with dementia.

However, the outcomes of this study also call for further consideration of the macro conditions which shape possibilities for improvements in the care of older people including those with dementia. The literature is replete with calls (Innes 2009; Downs, Small & 2006) that negative stereotypes associated with ageing and dementia, which are underpinned by stigma and discrimination must be re-shaped if opportunities for improving care provision are to be explored and realised. Indeed, ageist perspectives which prevail within western society impact not only on the quality of care that people with dementia receive, but also on who provides care and which aspects of caring are valued (Innes 2009, p.98-99). In particular, Nolan et al. (2004) suggest the lack of recognition and perceived low status of nursing and care work in RACFs is reflective of a wider public perception about the value of older people in society. Angus and Nay (2003) suggest that economic imperatives and resourcing issues that constrain care in RACFs, likewise reflect cultural values that marginalise the needs of older people who do not fit into the healthy ageing paradigm. Hence, it is augured (O’Connor 2009, p.267) that there is an imperative for future research to explore how dominant discourses around healthy, independent ageing have contributed to old, frail people being conceptualised as “decrepit”, and the death being framed “ordinary” or “routine” and thus devalued in social and financial terms.

Moreover, the tensions in relationships between nurses and PCAs exposed in this study arguably also reflect a wider discourse within the nursing profession that has progressively devalued “hands on” care, relegating it to those with less formal training (Herdman 2002; Nolan et al. 2004). Privileging of biomedical, technological and clinical aspects of nursing has meant that opportunities for collaboration and dialogue between PCAs and nursing staff remain deficient. Undoubtedly, there is an
imperative that researchers adopt more critical orientations to understanding the interests that shape care for people with dementia in RACFs, both at micro and macro levels and make this knowledge accessible within public and professional discourse. As part of this process, there is a growing recognition of the need for future research in dementia care to value “insider” knowledge (Small et al. 2007) as a way of explicating the complexity of dementia care. Therefore research predicated on working in partnership with people who have dementia and those who provide care for them, will provide valuable insights into the generation of this “insider” knowledge. Nolan and colleagues (2004, 2006) work around and the Sense Framework holds great promise for facilitating the development of a palliative approach to care through relationship-centred strategies. Indeed, while the best-practice Guidelines for a palliative approach in residential aged care (ADoHA 2006) highlight the importance of collaboration and positive relationships between staff, residents and families, strategies to actually facilitate this are crucial.

10.2.2 Fostering sustained engagement to support innovation

This study illustrates that the development of knowledge and practice to better support a palliative approach to care was reliant on building the capacity of staff members for leadership. Previous research that has attempted to improve the palliative care practices of aged care staff by the use of a change champion/agent has raised common problems (Maddocks et al. 1999; Froggatt & Hoult 2002; Hasson et al. 2008). In particular, the adverse impacts of demanding workloads and burnout of these staff as they attempt to foster change across various organisational levels is reported to undermine the extent and sustainability of improvements that can be gained (Hasson et al. 2008). In recognition of the heavy demands already placed on aged care staff, in terms of workloads, administrative requirements and resource availability, it does not seem practicable or realistic to expect one person, whether a nurse practitioner (Maddocks et al. 1999) or a link nurse (Hasson et al. 2008; Froggatt et al. 2002), to be responsible for the success of a change agenda. Field and Fitzgerald (2006) have argued that practice development should rest with an entire team, but have acknowledged that in reality this rarely happens and that often one or two people lead the way. In recognition of this situation, there is an imperative for researchers to explore methodological approaches that promote and sustain the development of a “critical mass of change champions” (Davies et al. 2007, p.65) within RACFs. Explicitly fostering such team approaches to change could create
more equitable distribution of knowledge and workloads amongst team members, thus contributing to a context better able to sustain the process of culture change.

However, the implications of appropriate resourcing must also be further explored in parallel with participatory models of research (Nolan et al. 2007a). Time and appropriate financial and human resources are crucial to the development of organisational infrastructure that will support aged care staff in pursuing long term change agendas. In support of this perspective, Abbey and colleagues (2006, p.59) have contended that sustainable change will not occur through “short-tem initiatives” but must be fostered through sustained engagement so that research and development activities are embedded and protected within these settings. Innovations within the UK that support formal collaborations between the care home sector and universities such as the “My Home Life programme” (Meyer & Owen 2008, pp.293-294), could provide the Australian aged care sector with many useful directions for such future development.

The establishment of formal collaborations between aged care providers and universities has been recognised as offering an ideal base for leadership in practice development (Davies et al. 2002). Given that people entering long-term care are more dependent (Andrews-Hall et al. 2007) and more likely to have some form of dementia (AIHW 2006b), long-term care settings have been recognised as potential locations for education around dementia and palliative care of student health care professionals (Wowchuk et al. 2006). Apropos this recommendation, the role of teaching nursing homes (TNHs) as centres of education and innovation in development of evidence-based practice has been identified (Kirkevold 2008; O'Connell et al. 2008). Having been well established in the USA (Shaughtessy et al. 1990) and more recently in Norway (Kirkevold 2008), the concept of TNHs is growing in the UK (Davies et al. 2002). There is evidence to suggest that TNHs offer potential benefits for students, staff and residents of facilities (Davies et al. 2002; Shaughtessy et al. 1990; Kirkevold 2008) and valuable opportunities for the development of care beyond the technical, task-oriented focus (evident in this study) (Davies et al. 2002; O'Connell et al. 2008). They also have the potential to be centres of excellence in specialised areas, such as dementia and palliative care (Kirkevold 2008). Establishing TNHs is reliant on strategic support from and ongoing collaboration with management of the aged care facilities (Kirkevold 2008). Hence, leadership and managerial commitment to evidence-based practice and associated
culture change may be harnessed and further promoted through alliances with educational institutions.

While there is increased interest in models for TNHs in Australia with some pilot work being conducted (O'Connell et al. 2008; O'Connell 2008), we have yet to make this cultural shift – the effects of which we continue to see in the poor recruitment of newly graduated nurses, poor retention rates of existing professional staff (AIHW 2008) and a sector that struggles to embrace evidence-based practice (Masso & McCarthy, 2009). There is an imperative that future research be conducted within Australia examining the establishment of TNHs and their benefits in terms of building leadership that can support innovation in practice development. Moreover, workforce implications as well as other social, financial and care-related outcomes for older people and their family caregivers require further exploration within the TNH model.

TNHs have the potential to be centres of research that can further explicate the interconnections between a palliative approach to care and other important philosophies of person-centred (Kitwood, 1990, 1993a, 1993b) and relationship-centred care (Nolan et al. 2004). Such future research will hopefully be a catalyst for greater discussion and debate across policy and aged care contexts about the need for national leadership in resourcing and funding aged care facilities to promote best-practice palliative care (Abbey et al. 2006). Through building organisational infrastructure that will enable staff to take a more proactive role in countering the marginalisation of their needs, those of older people both with and without dementia in RACFs, as well as their family caregivers; sustainable improvements in care delivery may be realised.

10.3 Reflections on my role as an action researcher and the research process

Conducted within the uncertainty of daily practice, action research makes numerous demands upon the facilitator and co-researchers, the politics of which cannot be easily dismissed (Morton-Cooper 2000). Given my novice status as an action researcher, the task of taking on the role of facilitator was daunting. Despite having read copious amounts of literature on action research and the various theoretical paradigms and practicalities of the research process, the complexity inherent in the role of facilitation became only truly “knowable” to me as I engaged in the process.
Street’s (1995, p. 173) observation that the role of research in collaborative inquiries is “fraught with anxiety” (Street 1995, p. 173) resonates strongly with my experience. I keenly felt the angst associated with negotiating my “competing positions” (Street 1995, p. 173) as researcher. At times, I felt as though I was caught in a schizophrenic dance between being a data collector, critical friend, collaborator in problem identification, PhD candidate accountable to my supervisors, and the organiser of afternoon teas for the ARG meetings – just to name a few roles.

My role within this study was also characterised by and insider/outsider duality. From one perspective I was an “outsider” – what Freire (Shore & Friere 1987, p.181-182) may call a member of “the academy”; a researcher pursuing a doctoral degree. Paradoxically, at the same time I was also an ‘insider’ – an aged care nurse and a previous co-worker of the ARG members. From the first ARG meeting I was aware of my shared status, because as suggested by numerous authors the operation of power relations is present in all interactions (Gaventa & Cornwell 2001; Foucault 1977b), including when researchers have an insider status (Herr & Anderson, 2005). When we met, the ARG members were familiar with me and in keeping with the perspective of Waterman and colleagues (2005, p. 283), I easily developed trust and a good rapport with the group. Conversely however, I felt uncomfortable raising the group members’ taken-for-granted assumptions about practice during the early reconnaissance discussions. Through my initial efforts I quickly learnt that the group too was not comfortable with me asking them to contest some of their understandings and practices. Indeed, some of these early attempts to critically engage the group were met with silence and at times discontent. At one point, the group members shared concerns about their sense of having to ‘explain themselves’ when they were asked to critically reflect on issues from case notes of their previous discussions.

My sense of discomfort was a useful reminder of the limited experience of staff in critically reflecting on their practice, which is evident in aged care literature (Chenoweth & Kilstoff 2002; Robinson 2005a) and literature about other areas of nursing practice (Stratton 2009; Robinson & Street 2004). Additionally, problems with the ARG meetings being interrupted and members having to leave to attend to “issues” on the unit – despite the presence of other staff cover – were instances that further suggested the alien nature of meeting to talk about and reflect on practice. Robinson (1995, p.70) has argued that the privileging of “doing” over “thinking” within nursing culture reflects a “regime of truth” that supports technologies of
“normalisation” that engender imperatives of efficiency or getting the work done. Therefore, as a facilitator of the research process I had to invest significant energy to ensure that the ARG members had a space for meeting where physical interruptions could be minimised, so that they remained engaged in dialogue around issues under discussion. I initially expected that the ARG members would review the case notes of the previous meeting and consider the key issues that were emerging prior to the next meeting. To me the researcher, this seemed an obvious course of action and one that we had discussed in our sessions about action research. It soon became evident however, that while the ARG members had read the case notes, they were struggling to find opportunities to critically reflect on them amidst the “busyness” of their everyday practice.

The reality of aged care practice is that staff are busy and time poor (Bowers et al. 2001), a factor which I do not wish to discount or minimise. The findings of this study speak to the pressures and demands of the environment on the practices of nurses and PCAs. However, the ARG’s reluctance to critically engage with the case notes outside the ARG meetings arguably revealed what Foucault (1977b, p.97) has called the “real effects” of power. Herein, the culturally inscribed understandings of their roles as shaped around “doing” came to expression. This finding demonstrated that the development of a collaborative, critical ethos amongst the group required significantly more facilitation from me. Therefore, at the beginning of each meeting, I would review the case notes from the previous meeting with the group, discuss the key issues that were emerging, consider our location within the action research cycle and track emerging critically reflective insights of our discussions on a whiteboard. In this sense, my role as an “outsider” researcher was helpful, because in this position I was readily able to ask the group to participate in activities designed around building a critical orientation. During the first 4 to 5 months of the project I engaged the ARG members with these strategies at each meeting. As the process unfolded, group members developed more critical orientations as they engaged in telling their stories from practice.

As the research progressed, I became aware of the group members’ sense of powerlessness with their current situation. In parallel with this insight, I developed a growing concern that my critical probing, which emerged in part from my insider knowledge of the politics of care in the SCU, might be expressed as an exercise of
power in the research process. An account from my research journal captured this experience when I noted:

...as I work with the ARG members to critically reflect on their practices, I get the sense that some of the members feel like they are breaking some type of cultural rule by exposing the realities of their practice in response to my critical questioning... as the (???) expert researcher.

Mason and Boutlier (1996) have pointed out that asymmetrical power relations between the researcher and co-researchers are “inextricably linked” to the relative positions of people within the organisation in which they work. Thus, as a member of a university I could not escape my seemingly more “expert status” (particularly since none of the ARG members had attended university). Therefore, in keeping with Hall (1996, p.47), it was important for me to “‘own up’” to my own “personal contributions in the process of knowledge construction”. Regular journaling enabled me to interrogate my position(s) (Herr & Anderson 2005, p.44) in the research and record my “self-doubts”, which according to Meyer (1993) can be rife for doctoral candidates.

Journaling also enabled me to map the strategies that I employed to encourage the development of collaborative, reciprocal relations between myself and the group members. A key contribution of my efforts to develop reciprocity in the research was my facilitation role in the group’s preliminary investigation during stage one of the study. I assisted the group to learn about the research method and engage in collaborative dialogues, in addition to developing and administering questionnaires, an audit tool and conducting stakeholder interviews. Providing a plethora of data to the ARG members about their palliative care practices facilitated what Lather (1991, p.57) has referred to as “collaborative theorising”. I was surprised by the massive amount of work that I was required to undertake within only the first stage of the study in order to ensure that the group members’ emerging analyses of their practice was based in democratic processes of knowledge development. Driven by my awareness, as a novice action researcher, of the need for rigorous data from which the group could make critically-informed decisions, I engaged in what Street (1995, p.184) has referred to as “a diligent search for certainties”, only to find that I was forever being confronted with increasing complexity. Collecting and analysing what became vast amounts of data, and then presenting it to the ARG members for their further analysis, took a significant amount of time and energy for all of us. In the
context of a doctoral project, which by its very nature has temporal limits, the ARG members signalled a sense of never-ending data and ‘not enough action’ as Judy put it.

Therefore, by the time the ARG had participated in the action planning workshop we were all feeling a sense of relief that we were moving ahead. Even though I continued to resource the group during Stage Two of the project as they planned their intervention strategies (e.g. case notes, helping develop forms and evaluations), the members were responsible for choosing the direction of the interventions, in keeping with the collaborative participatory foundations of critical action research. I was equally aware that I had, as I wrote in my journal ‘made a commitment to journey with the group as they sought to address pressing issues of concern in their practices’. The “ambitious” (p.207) nature of the intervention strategies that the group planned was highlighted by the project steering committee. As the group members implemented their action plans the need for more realistic resourcing became evident, as did the reality that we may have been over-enthusiastic in our intentions. The group’s exhaustion at the end of the project suggested a need to have done less, given that staffing and workloads presented significant structural barriers to initiating change. Street (1995, p.122) has pointed out that there is a limit to change that can be effectively initiated and managed within a specific setting. Herein lies a tension of facilitation, as there is an imperative by the researcher to promote and support egalitarian decision-making toward action, but paradoxically this may constrain the extent of change that can be achieved as people become fatigued by the process.

Interestingly, a key concern for some of ARG members, which was raised in their reflections in Chapter 9 (p. 264), was their perceptions of not having done enough. Arguably, these concerns relate the group members’ recognition of the range of deficiencies that were exposed in their practices during the preliminary investigation and a desire for greater change. This situation highlights the ethical challenges for action researchers working with staff as co-investigators who are sensitive to problems in the practice but at the same time have a finite ability to support a change agenda over a sustained period of time. Herein, it was incumbent upon me to revisit with the group the improvements that they had achieved and reiterate the importance of incremental change which did not occur easily for the group, but through “struggle[s]” (Kemmis & McTaggart 1988, p.26) with what were at times highly
resistant social, material and political conditions. Working with the ARG for approximately 21 months enabled me to re-engage their attention to this very important aspect of their journey. However, having had close contact with these staff members for just shy of two years also meant that there was potentially ethical implications associated with my withdrawal from the field at the end of the project. Koch and Kralik (2006, p. 115) have pointed out that in a facilitated, participatory inquiry “disengagement” of the researcher can be ethically problematic when people have established reciprocal relationships. This was a concern of mine, especially for the PCAs of the group, for whom the research had provided an opportunity to have voice about issues in the care of people with dementia and their role on the SCU.

As the project drew to a close however, I had limited opportunity to explore these ethical implications with the ARG members. As outlined in Chapter 9 (p.263) the groups members’ efforts to engage in the research on top of their existing work demands meant that they were relieved by their decision to discontinue the palliative care planning pilot and that their participation in the project had finished. From this perspective it could be argued that the project, my withdrawal from the field and the relationships established with the ARG came to a natural end. Yet despite the ARG members’ fatigue, their final reflections (presented earlier in this chapter), suggested that they had experienced what Kemmis and Wilkinson (1998, p.21) have described as “a strong and authentic sense of development and evolution in their practices, their understandings of their practice and the situation in which they practice”. This sentiment is perhaps best captured in the parting comments of Catherine, who stated: ‘I really appreciate the opportunity to be part of the project, it was a real privilege’.

10.4 Limitations of the study

There are a number of limitations to this study that need consideration. Firstly, data collection occurred in one SCU. Hence, the views of aged care staff (via ARG meetings, critical dialogues, and surveys), family caregivers (via interviews) and other key stakeholders (via critical dialogues) were collected from small samples of participants, using convenience sampling. Likewise the number of resident files audited (n=21) was small. These factors limit the extent to which the study findings represent current practice and peoples’ understandings about aspects of dementia and palliative care beyond the research setting. It may be argued however, that the problems associated with the small samples used to inform the study may, to some extent, be mitigated through the triangulation of data collection methods. When
considered together (see Appendix 16), the data from the documentation audit, critical dialogues with stakeholders, family caregiver interviews and surveys, present a compelling picture supporting the concerns of the ARG members.

While the survey tools (PAQ and the KDQ), used in stage one of the project were developed though a rigorous process, the internal consistency reliability of the PAQ (alpha coefficient = 0.68) was found to be on the border of “questionable/acceptable” and the KDQ had “questionable” (George & Mallery 2003, p.231) reliability (KR21=0.62). The low reliability scores for both tools could be reflective of a number of factors such as the instruments not having enough items, the sample of respondents being too small or the items in the tools having too much heterogeneity (Nunnally & Bernstein 1994). With these limitations in mind the findings for the PAQ and KDQ need to be interpreted with some caution, suggesting that further work is needed to ensure the internal reliability and stability of the tools over time (Nunnally & Bernstein 1994). The reliability of the audit data could also be questioned as I was the only person responsible for collection. Even though I checked each of the resident’s files twice after the first audit for inconsistencies in the data, the use of two auditors would have improved the reliability of information collected.

Additionally, the perspectives of casual staff working in the SCU were not elicited in this study. It has been reported that there is an increasing casualisation within the aged care workforce (Martin & King 2008). Thus, not including these staff members potentially limits applicability of the findings to RAC settings that have a high turnover of staff and use more casual employees. Perspectives of other staff such as ancillary staff, allied health staff and management staff were also not included, nor were those of staff not working in a SCU. These limitations suggest the need for similar studies to be conducted not only in a range of SCUs but also in the general RACF setting.

10.5 Final remarks

As stated in Chapter 1, this thesis chronicles the journey of members of an ARG who engaged in a critical action research process to address the question: *What are the possibilities for aged care staff to develop their practices around a palliative approach to care for people with dementia and their family caregivers?* Despite the numerous challenges encountered during their journey, particularly with respect to a
lack of resourcing and organisational infrastructure to support an action research project, it could be argued that their journey – indeed our journey – was one of discovery and hope.

This study delved into the micro-politics of an aged care setting, to flesh out the complex and often competing interests that shape the capacity of aged care staff to develop their practices in ways that support a palliative approach to care for people with dementia. To date, few studies (Jervis 2002; McInerney et al. 2009; Angus & Nay 2003) have sought to critically explore and explicate the socio-political interests and cultural conditions of aged care settings and more specifically the impact of these conditions on the ability of staff to deliver a palliative approach (Phillips et al. 2008). Yet, as demonstrated in this study a critical exploration of these issues was essential for ARG members to arrive at new understandings about the possibilities for developing their practices. Nonetheless, this was a challenging endeavour. At the beginning of the project the ARG members were isolated individuals in practice, disempowered by the hegemony of institutional interests and hierarchical care arrangements. It is hardly surprising that initially they were unable to envisage how they might practice differently. Yet, each of these staff members shared “deeper stirrings” (Reason & Bradbury 2001c, p.7) to improve the care that they provided for people with dementia and family caregivers of the SCU.

Bringing the ARG members together in a critical agenda, where they could constitute a “communicative space” (Habermas 1996) created possibilities for them to develop radically different understandings about their practices. The outcomes of their critical, dialogic engagement reaffirmed the observations of Giddens (1979 p.71), that people “are not cultural dopes”. Rather, when given adequate opportunity the ARG members exposed taken-for-granted assumptions and actions that were antithetical to developing their practices around a palliative approach to care. As a result, these group members confronted what Fals Borda (2001, p.28) refers to as the “painful confirmation” of their own collusion in sustaining unjust circumstances. The group members’ increasingly sophisticated understandings of their reality highlighted the centrality of collaboration and reciprocity as key strategies which give voice to the knowledge and experience of practitioners and opens up possibilities for practice development.
As the ARG members critiqued their assumptions and practices, they, like me, were faced with “uncertainty” (Street 1995, p.183). As new insights and issues emerged so did a sense of indeterminacy about where our subsequent research activities would take us. However, this did not dissuade the group members in their efforts to address what they considered were unjust circumstances for people with dementia and their family members. Through their commitment to pursue a transformative agenda, the ARG achieved change though what Kemmis and McTaggert (1988, p.35) have referred to as “struggles” with material, social and cultural interests that had shaped their practices. Arguably, the dedication of these staff to engage in the “process” (Kemmis & McTaggart 1988, p.26) of change reflects a shared, authentic hope that through action they could improve the provision of palliative care for residents in the SCU.

In conclusion, this study highlights that possibilities for developing the practices of aged care staff around a palliative approach emerge through the development of critical, collaborative partnerships whereby staff members can become active agents in knowledge development and change. This point on participation and partnership cannot be overstated. Yet equally, the findings also suggest that within RACFs there must be systems that can support change. Hence there is an imperative that future research in the aged care setting focuses on strategies for building leadership to support innovation in the delivery of palliative care. As the number of older, frailer people with dementia entering RACFs increases, so will the imperative for care framed by a palliative approach that is flexible, responsive and founded in humanistic values. The provision of such care, which Friere (1970) might describe as “humanizing” (p.50), relies on working in “communion” (p.43) with aged care staff to expose the oppressive aspects of their reality that constrain the implementation of best practice for people living and dying with dementia, as well as their family caregivers.


AIHW 2004b, *The impact of dementia on the health and aged care systems*, cat. no. AGE 37. Canberra, AIHW.

AIHW 2006a, *Chronic disease and associated risk factors in Australia*, 2006, cat. no. PHE 81. Canberra, AIHW.

AIHW 2006b, *Dementia in Australia: national data analysis and development*. Canberra, AIHW.


Aranda, S & Street, A 2001, 'From individual to group: use of narratives in a participatory research process', *Journal of Advanced Nursing*, vol. 33, no. 6, pp. 791-797.


Australian Department of Health and Ageing 2003, *Community Attitudes to Palliative Care Issues*, ADoHA, Rural Health and Palliative Care Branch, Canberra.


Aveyard, B & Davies, S 2006, 'Moving forward together: evaluation of an action group involving staff and relatives within a nursing home for older people with dementia', *International Journal of Older People Nursing*, vol. 1, no. 2, pp. 95-104.


Birch, D & Draper, J 2008, 'A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia', *Journal of Clinical Nursing*, vol. 17, no. 9, pp. 1144-1163.


Blue Mountains Division of General Practice, University of Western Sydney & South Western Area Health Service 2006, Information for family and friends of people with severe and end stage dementia, University of Western Sydney, NSW.


Chang, E, Daly, J, Harrison, K, Easterbrook, S, Bidwell, J, Stewart, H, Noel, M & Hancock, K 2009, 'Challenges for professional care of advanced dementia', *International Journal of Nursing Practice*, vol. 15, pp. 41-47.


Chenoweth, L & Kilstoff, K 2002, 'Organizational and structural reform in aged care organizations: empowerment towards a change process', *Journal of Nursing Management*, vol. 10, no. 4, pp. 235-244.


Crotty, M 1998, The foundations of social research: meaning and perspective in the research process, Allen and Unwin Pty Ltd, St Leonards.


Ersek, M, Miller Kraybill, B & Hansberry, J 1999, 'Investigating the educational needs of licensed nursing staff and certified nursing assistants in nursing homes regarding end-of-life-care', American Journal of Hospice and Palliative Care, vol. 16, no. 4, pp. 573-582.


Ezzy, D 2002, Qualitative analysis, practice and innovation Allen and Unwin, Crows Nest.


Field D, & Addington-Hall, J 1999, 'Extending specialist palliative care to all?', Social Science and Medicine, vol. 48, pp. 1271-1280.


Froggatt, K 2001a, 'Life and death in English nursing homes: sequestration or transition', Ageing and Society, vol. 21, pp. 319-332.


Gibb, M 2002, 'Doing a doctorate using a participatory action research framework in the context of community health', *Qualitative Health Research*, vol. 12, no. 4, pp. 546-558.


Grbich, C, Maddocks, I, Parker, D, Piller, N, Brown, M & Willis, E 2003, *Palliative care in aged care facilities for resident with non-cancer diagnoses*, 304
Department of Palliative and Supportive Services, School of Medicine, Flinders University, Adelaide.


Haesler, E, Bauer, M & Nay, R 2006, 'Factors associated with constructive staff-family relationships in the care of older adults in the institutional setting',


Hansen, E 2006, Successful qualitative health research, Allen and Unwin, Crows Nest.


Holter, IM & Schwartz-Barcott, D 1993, 'Action research: what is it? How has it been used and how can it be used in nursing?', *Journal of Advanced Nursing*, vol. 18, pp. 298-304.


Hughes, JC, Hedley, K & Harris, D 2004, 'The practice and philosophy of palliative care in dementia', *Nursing & Residential Care*, vol. 6, no. 1, pp. 27-30.


Jeong, SY & Mcmillan, M 2003, 'Documentation leads to reform: reality or myth', *Geriaction*, vol. 21, no. 4, pp. 22-25.

Jervis, LJ 2002, 'Working in and around the 'chain of command': power relations among nursing staff in an urban nursing home', *Nursing Inquiry*, vol. 9, no. 1, pp. 12-23.


Kitzinger, J 1994, 'The methodology of focus group interviews: the importance of interaction research participants ', *Sociology of health and illness*, vol. 16, pp. 103-121.


Mass, M, Reed, D, Park, M, Specht, J, Schutts, D, Kelley, L, Swanson, E, Tripp-Reimer, T & Buckwalter, K 2004, 'Outcomes of family involvement in care intervention for caregivers of individuals with dementia', *Nursing Research*, vol. 53, no. 2, pp. 76-86.


McTaggart, R & Garbutcheon-Singh, M 1986, 'New Directions in Action Research', Curriculum Perspectives, vol. 6, no. 2, pp. 42-46.


Moore, K & Haralambous, B 2007, 'Barriers to reducing the use of restraints in residential elder care facilities', *Journal of Advanced Nursing*, vol. 58, no. 6, pp. 532-540.


Morrison, RS & Sui, AL 2000b, 'Survival in end-stage dementia following acute illness', *Journal of the American Medical Association*, vol. 284, pp. 47-52.


Nolan, M, Hanson, E, Grant, G & Keady, J (eds.) 2007b, *User participation in health and social care research: voices, values and evaluation*, Open University Press, Berkshire.


Nolan, MR & Dellasega, C 1999, 'It's not the same as him being at home': creating caring partnerships following nursing home placement', *Journal of Clinical Nursing*, vol. 8, pp. 723-730.


PCA 2005b, *Standards for providing quality palliative care for all Australians*, Palliative Care Australia, Canberra.


Riley, R & Manias, E 2002, 'Foucault could have been an operating room nurse', Journal of Advanced Nursing, vol. 39, no. 4, pp. 316-324.


Rumbold, B 1998, 'Implications of mainstreaming hospices into palliative care services', in J Parker & S Aranda (eds.), *Palliative care: exploration and challenges*, Maclennan & Petty, Sydney, pp. 3-20


Rutman, D & Parke, B 1992, 'Palliative care needs of residents, families, and staff in long-term care facilities', *Journal of Palliative Care*, vol. 8, no. 2, pp. 23-29.


Sandelowski, M 1995, 'Qualitative analysis: what is it and how to begin', *Research in Nursing and Health*, vol. 18, no. 4, pp. 371-375.


Spear, H 2006, 'Evidence -based nursing practice: making progress and making a difference', *Worldviews on Evidence Based Nursing*, vol. Second Quarter, pp. 52-54.


Stratton, B 2009, *Developing nursing practice to meet the needs of older adults in an Australian day procedure unit - an action research study*, Unpublished PhD thesis, University of Tasmania, Australia.

Street, A 1990, *The practice of journaling for teachers, nurses, adult educators and other professionals*, Deakin University, Melbourne.


Strumpf, NE, Tuch, H, Stillman, D, Parrish, P & Morrison, N 2004, 'Implementing palliative care in the nursing home', *Annals of Long-Term Care*, vol. 12, no. 11, pp. 35-41.


Teno, JM 2003, 'Now is the time to embrace nursing homes as a place of care for dying persons', *Journal of Palliative Medicine*, vol. 6, no. 2, pp. 293-296.


White, M 1992b, 'Family therapy training and supervision in a world of experience and narrative', in *Experience and contradiction, narrative and imagination*, Dulwich Centre Publications, Adelaide.


White, M 2004a, 'Working with people who are suffering the consequences of multiple trauma: a narrative perspective', *The International Journal of Narrative Therapy and Community Work*, no. 1, pp. 44-75.


Appendices