Navigating a palliative approach in residential aged care using a population based focus

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A thesis submitted in fulfillment of the requirements for the degree of

Doctor of Philosophy

School of Nursing
College of Health & Science
2008
I, Jane Louise Phillips, declare that this Thesis, submitted in fulfillment of the requirements for the award of Doctor of Philosophy, in the School of Nursing, College of Health & Science, University of Western Sydney, is wholly my own work unless otherwise referenced or acknowledged. This document has not been submitted, either wholly or in part, to any other educational institution.
Dedicated to:

The many older people residing in our aged care facilities whose fragility, voicelessness and significant care needs have been a constant source of inspiration to remain on this pathway.
ACKNOWLEDGEMENTS

Undertaking a PhD is a voyage of discovery which is full of memorable experiences and enriching encounters. Many of the people I have met whilst on this journey have contributed to this research through their generous gifts of time, advice, support and encouragement.

My initial thanks goes to Dr Terrance Hays, who having challenged and inspired me to embark on this pathway has continued to been an ongoing source of support and encouragement.

Professor Patricia Davidson has afforded me a stellar supervision experience, one which I aspire to replicate. I will forever be grateful for Patricia’s enthusiasm, intellectual wisdom, generosity, and above all her ability to be a critical friend. Her mentoring has inspired me to venture further than I had imagined possible.

I would also like to acknowledge the wonderful guidance provided by the other members of the supervision panel, Professor Debra Jackson, Professor Linda Kristjanson and Professor John Daly. Special thanks also to Associate Professor Richard Ollerton for his expert statistical advice and to Dr Simon Willcock for assisting with the general practitioner focus groups.

My appreciation to the Commonwealth Department of Health and Ageing, National Palliative Care Program and the Mid North Coast (NSW) Division of General Practice who provided the opportunity and support to undertake this research as part of a larger national initiative. Special thanks to Peter Spence, Dr David Ellis and Rita Evans for their belief in the value and importance of this endeavour.

My sincere gratitude goes to the directors of nursing, aged care nurses and care assistants who have all played a major role in this research. These aged care providers were generous with their time and provided me with many important insights. I am also indebted to my palliative care nursing colleagues, Penny West and Paula Hickman who shared the project’s vision and to Bev Morris and Dr Deborah Prior for their assistance with implementing discrete aspects of the learning and development strategy.

I have been honoured to have met others whose collaborative endeavours have enriched this journey. Special thanks go to Professor Victor Minichiello, Dr Elizabeth Halcomb, Dr Michelle DiGiacomo, Louise Hickman and Phillip Newton for their collegiality, support and friendship.

Lastly my heartfelt gratitude to my husband David, for his patience, love and support throughout this journey, and to my parents, Betty and Les who sacrificed so much to ensure that I had the opportunities that they only dreamed of.
ABSTRACT

Changes in demographic patterns and the burden of chronic illness have challenged palliative care clinicians to engage populations other than those with malignant disease. This new paradigm has promoted the development of a population based approach to service delivery which aims to extend the reach of palliative care to hard to reach populations, including older people in residential aged care. In Australia, the high levels of disability and death experienced by older people in this care setting has resulted in policy promoting the delivery of a palliative approach to care. Achieving health care reform in this complex health care environment has traditionally been difficult to realise due to a range of workforce, training, funding, variable organizational philosophies and legal factors.

The “Residential - Palliative Approach Competency” (R-PAC) Project aimed to collaboratively develop, implement and evaluate a sustainable model of care to facilitate the delivery of a palliative approach to care for older people admitted to residential aged care facilities, in regional Australian. Action research, with a focus on improving care and involving participants, was used to promote the delivery of a palliative approach in residential aged care facilities.

The R-PAC Project was designed to follow the action research sequence of reflection, assessment, planning, action and observation. Nested within the action research method are eight distinct but interrelated studies in a mixed method design. Study A, a focused needs assessment undertaken as part of the preliminary investigations, confirms that older people in aged care have unmet palliative care needs. The three studies conducted during Phase One provide a greater understanding of delivering palliative care in the residential aged care setting. Study B, a chart audit identified the strengths and gaps in end-of-life care provision in the local aged care setting. While, Study C identified that aged care nurses and care assistants are committed and compassionate about delivering palliative care but desired greater palliative care competencies. The palliative care attitudes, values and learning needs of aged care providers were explored in greater depth in Study D.
The data from these investigations guided the development and implementation of a multi-faceted intervention during Phase Two. Following the implementation of the multi-faceted intervention and during Phase Three another series of investigations was undertaken to measure the impact of the collaborative intervention. Focus groups were used to determine the perceptions of aged care providers toward the multi-faceted intervention (Study E) and to seek the views of general practitioners (Study F). These data revealed that aged care nurses and general practitioners wanted to establish a more collaborative approach to care planning and delivery. The survey (Study G) and chart audits (Study H) were repeated in Phase Four in order to measure the impact of the action. The findings of the survey of aged care nurses and care assistants shown an increase in palliative care competencies, while the chart audit demonstrated positive trends in improving end-of-life care. Although, some aspects of care, particularly advance care planning and routine use of pain assessment tools required ongoing attention. This data propel the R-PAC Project into Phase Five and the development of a model of care to promote the delivery of a palliative approach, which was informed by the research findings.

The R-PAC Project use of the action research method has facilitated a cascade of engagement and participation of all residential aged care facilities in this regional community and enabled practice innovation. The project has seen the sharing of valuable insights into usual practice and collaboratively engaging aged care nurses, care assistants and general practitioners in developing practical solutions to end-of-life care. This process has allowed for the acknowledgement and validation of the role of aged care providers, fostered personal empowerment and identified the importance of collaboration. This research has provided greater insight into the palliative care needs of people in residential aged care and collaboratively developed an intervention to improve the outcomes of older people. Study findings have also identified important issues requiring ongoing evaluation, particularly multidisciplinary team meetings and care planning.
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BOOK CHAPTERS


INVITED PRESENTATIONS


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<th>Definition</th>
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<tr>
<td>AHS</td>
<td>Area Health Service</td>
</tr>
<tr>
<td>AIN</td>
<td>Assistant in Nursing</td>
</tr>
<tr>
<td>CA</td>
<td>Care Assistant</td>
</tr>
<tr>
<td>CNC</td>
<td>Clinical Nurse Consultant</td>
</tr>
<tr>
<td>DNR</td>
<td>Do Not Resuscitate</td>
</tr>
<tr>
<td>EN</td>
<td>Enrolled Nurse</td>
</tr>
<tr>
<td>FTE</td>
<td>Full Time Equivalent</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HREC</td>
<td>Human Research Ethics Committee</td>
</tr>
<tr>
<td>IDC</td>
<td>Indwelling Catheter</td>
</tr>
<tr>
<td>LGA</td>
<td>Local Government Area</td>
</tr>
<tr>
<td>MDT</td>
<td>Multidisciplinary Team</td>
</tr>
<tr>
<td>N/A</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>NALAG</td>
<td>National Association of Loss and Grief</td>
</tr>
<tr>
<td>NH&amp;MRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>NUM</td>
<td>Nursing Unit Manager</td>
</tr>
<tr>
<td>PCA</td>
<td>Personal Care Assistant</td>
</tr>
<tr>
<td>PDSA</td>
<td>Plan-Do-Study-Act</td>
</tr>
<tr>
<td>PRN</td>
<td>As required</td>
</tr>
<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
</tr>
<tr>
<td>RCS</td>
<td>Residential Classification Scale</td>
</tr>
<tr>
<td>RN</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>R-PAC</td>
<td>Residential Palliative Approach Competency Project</td>
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<tr>
<td>RPCP</td>
<td>Rural Palliative Care Program</td>
</tr>
<tr>
<td>S/C</td>
<td>Subcutaneous</td>
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<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>TAFE</td>
<td>Tertiary and Further Education</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>UWS</td>
<td>University of Western Sydney</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td><strong>GLOSSARY</strong></td>
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<td><strong>Care Assistant</strong></td>
<td>A generic term that refers to a wide range of non professional workers who work in residential aged care, many of whom are unregulated and have limited training. These workers deliver direct personal care to residents and are often referred to as an ‘Assistant in Nursing’, ‘Personal Care Assistant’ or ‘Personal Carer’(^{(1)}).</td>
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<td><strong>Changeability</strong></td>
<td>The degree to which a specific health related factor is likely to be amenable to change(^{(2)}).</td>
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<td><strong>Critical Reference Group</strong></td>
<td>Interested stakeholders with a shared concern or whose situations are problematic, who agree to become action research partners and engage in a process whereby they reflect on their experiences and collaboratively identify workable solutions and strategies(^{(3)}).</td>
</tr>
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<td><strong>Enrolled Nurse</strong></td>
<td>A person who has undertaken a 12 month training program, usually in a College of Technical and Further Education and is licensed under an Australian State/Territory Nurse Act to provide nursing care under the supervision of a Registered Nurse(^{(4)}).</td>
</tr>
<tr>
<td><strong>Level Five Hospital</strong></td>
<td>In NSW the level of a service describes the complexity of the clinical activity undertaken by a hospital, and is chiefly determined by the presence of medical, nursing and other health care personnel who hold qualifications compatible with the defined level of care. The levels of services provided in NSW range from 1 to 6, with level 6 hospitals providing the most complex services(^{(5)}).</td>
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<td><strong>Link Nurse</strong></td>
<td>A registered nurse who has developed an interest, received training and pursues ongoing education in the philosophies, principles and practices of a particular speciality (e.g. palliative care, diabetes, wound care)(^{(6-9)}). Although, not having the require competencies of an expert, the link nurse understands and promotes the knowledge, skills and attitudes of the speciality and maintains links with relevant experts(^{(9)}).</td>
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<tr>
<td><strong>Methodology</strong></td>
<td>The researchers’ approach to systematic inquiry based on the assumptions of their research paradigm, including: qualitative, quantitative and mixed methods(^{(10, 11)}).</td>
</tr>
<tr>
<td><strong>Palliative Approach</strong></td>
<td>Refers to a type of care that focuses on improving the older person’s level of comfort and function, while maintaining their dignity. It ‘…aims to improve the quality of life for individuals with a life-limiting illness or who are dying due to the ageing process, and their families, by reducing their suffering through the early identification, assessment and holistic treatment of pain, physical, psychological, social, cultural and spiritual...’</td>
</tr>
</tbody>
</table>
needs\(^{(1)}\) (p.221). It is care that commences well before the terminal phase of illness and acknowledges the needs of families and carers\(^{(1)}\).

**Paradigm**

‘A conceptual model of a person’s world view’\(^{(11)}\) (p.712). A paradigm consists of a range of philosophical assumptions that inform the research approach adopted\(^{(10, 12)}\). As it is socially constructed and its discourse is historically and culturally embedded, it tends to be constantly evolving\(^{(11)}\). A Paradigm includes beliefs related to the nature of reality (ontology), nature of knowledge (epistemology), and approach to systematic inquiry (methodology)\(^{(10)}\).

**Person responsible**

This term is used in NSW to determine which person has the legal ability to make care decisions if a person is unable to do so due to incapacity\(^{(13)}\). The person responsible is not necessarily the patient’s next of kin. ‘The person responsible is either:

- a guardian (including an enduring guardian) who has the function of consenting to medical, dental and health care treatments; or if there is no guardian:
- the most recent spouse or de facto spouse with whom the person has a close, continuing relationship. ‘De facto spouse’ includes same sex partners; or if there is no spouse or de facto spouse:
- an unpaid carer who is now providing support to the person or provided this support before the person entered residential care or, if there is no carer; or
- a relative or friend who has a close personal relationship with the person\(^{(13)}\).

**PRECEDE**

A health planning framework that facilitates the systematic evaluation of the needs of the target population by exploring their quality of life and the behavioural, environmental, predisposing, reinforcing, and enabling factors that impact on health and wellbeing\(^{(2)}\).

**Residential Aged Care**

Regulated accommodation that is available for older persons who require ongoing assistance with activities of daily living and nursing care. It is synonymous with nursing homes, assisted living facilities and hostel style accommodation\(^{(14)}\).

**Registered Nurse**

A person who has undertaken a basic education program (now university based) of not less than three years and is licensed to practice nursing under an Australian State/Territory Nurses Act\(^{(4)}\).
REFERENCE LIST


Chapter 1.

Introduction: A Population Based Approach to Palliative Care in Residential Aged Care in a Regional Australian Community
'Never doubt that a small, group of thoughtful committed citizens can change the world. Indeed it is the only thing that has’  

MARGARET MEAD

1.1 Introduction

Globally clinicians are investigating more inclusive, equitable and accessible models of palliative care that address changing epidemiological trends, particularly ageing and increasing chronic conditions\(^{1-4}\). The *Residential Palliative Approach Competency (R-PAC) Project* was designed to address the unmet needs of older people requiring palliative care services in residential aged care in a regional community setting. This chapter will provide the context and background to the R-PAC Project and an overview of the thesis.

1.2 Impetus for the R-PAC Project

The R-PAC Project is one component of the Mid North Coast Rural Palliative Care Project. Briefly, the Mid North Coast, New South Wales (NSW) Division of General Practice was one of eight rural divisions in Australia that was funded as part of the National Rural Palliative Care Program (2004 -2006) (Figure 1-1). The aim of the National Rural Palliative Care Program was to strengthen local partnerships to improve the coordination and delivery of local palliative care services\(^{5}\). To assist with the systematic identification of local palliative care priorities, a focussed needs assessment was undertaken upon commencement of the Mid North Coast Rural Palliative Care Project. This focussed palliative care needs assessment identified a range of potential priorities for action including, better engagement of local health care organisations and providers in the delivery of palliative care, establishing an after-hours palliative care service, enhancing health care providers’ palliative care competencies, and addressing the unmet palliative care needs of older people in residential aged care. These findings promoted the formation of a range of partnerships with local health care providers and services to collaboratively address these issues. These partnerships have resulted in the: establishment of a local palliative care network; a weekly, multidisciplinary multi-agency, palliative care planning forum; mapping of palliative care patients’ clinical care needs; trialling palliative care clinical indicators; use of end-of-life care pathways in the public and private acute care settings; establishment of an after-hours telephone support service\(^{6}\); and the enhancement of palliative care delivery in local residential aged care facilities.
CHAPTER ONE

INTRODUCTION

Figure 1-1 Conceptual relationship of the R-PAC Project to other initiatives

Establishing a collaborative partnership with local aged care providers to address the unmet palliative care needs of older people in residential aged care marked the commencement of the R-PAC Project. As the R-PAC Project was undertaken as a discreet arm of the Mid North Coast Rural Palliative Care Project and was the intellectual work of the doctoral candidate, permission was sought from the funding body and the fund recipient, namely Ms Rita Evans, Director of the National Palliative Care Program and Dr David Ellis, Chief Executive Officer Mid North Coast Division of General Practice to undertake this research. Both enthusiastically endorsed the decision by the researcher to undertake the R-PAC Project as a doctoral study (Appendix 1). Permission was provided to the doctoral candidate researcher and no embargo or sanction was placed on the collection, analysis, interpretation, or publication of data related to the R-PAC Project. However, the researcher was encouraged to use the compendium of survey tools developed for the National Rural Palliative Care Program\(^7\).

1.3 Aims

The R-PAC Project sought to collaboratively develop, implement and evaluate a sustainable model of care to facilitate the delivery of a palliative approach to care for older people admitted to residential aged care facilities in Coffs Harbour Local Government Area (LGA).
The specific research questions which the R-PAC Project sought to answer were:

1. What are the population based palliative care needs of older people living in residential aged care in Coffs Harbour, New South Wales?

2. What are the key factors in facilitating palliative care delivery in residential aged care in Coffs Harbour, New South Wales?

3. What are the major barriers to palliative care delivery in residential aged care in Coffs Harbour, New South Wales?

4. What are the palliative care knowledge, skills, attitudes and beliefs of clinicians working in residential aged care in Coffs Harbour, New South Wales?

5. What are the information needs, resources and systems required for the successful delivery of a palliative approach to end-of-life care in residential aged care facilities in Coffs Harbour, New South Wales?

6. What are the key components of a sustainable model of care to facilitate the delivery of a palliative approach to the end-of-life care for older people in residential aged care in Coffs Harbour, New South Wales?

1.4 Structure of the Thesis

Action research is a term that is applied to a range of research endeavours in which the researcher and participants collaborate to address practical problems in specific situations that leads to practice change and the development of theory\(^{(8)}\). Action research has been found to be useful in facilitating respectful cooperative and inclusive relationships with practitioners, enabling the naming of problems and identification of contextually appropriate and sustainable solutions\(^{(9)}\). This emphasis on improving and involving\(^{(10)}\) meant that action research was considered to be the methodology most likely to engage aged care providers in the study setting.

The R-PAC Project consists of eight sub-studies\(^{11-16}\), configured in a sequential transformative mixed method design\(^{(17)}\) undertaken during five action research phases. This linearity, in some ways disguises the complexity of the dynamic action research approach but has been reported in this way to increase clarity for the reader\(^{(18)}\). Table 1-1 is provided as a navigational tool to help guide the reader through the R-PAC Project action research phases.
This table provides an overview and describes the individual sub-studies and their location in this thesis.

**Table 1-1: R-PAC Project’s navigational tool**

<table>
<thead>
<tr>
<th>SEQUENCE</th>
<th>CONTENT</th>
<th>CHAPTER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preliminary</td>
<td>Setting the scene</td>
<td>One</td>
</tr>
<tr>
<td>Investigations</td>
<td>• Introduction to R-PAC Project</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Preliminary investigations</strong></td>
<td>Two</td>
</tr>
<tr>
<td></td>
<td>• Study A: A focused needs assessment</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Mapping out a process for action</strong></td>
<td>Three</td>
</tr>
<tr>
<td></td>
<td>• Methodological and conceptual approach</td>
<td></td>
</tr>
<tr>
<td>PHASE 1</td>
<td><strong>Developing priorities for action</strong></td>
<td>Four</td>
</tr>
<tr>
<td></td>
<td>• Study B: Time 1, chart audit end-of-life care</td>
<td></td>
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<tr>
<td></td>
<td>• Study C: Time 1, focus groups aged care staff</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Study D: Time 1, survey aged care staff</td>
<td></td>
</tr>
<tr>
<td>PHASE 2</td>
<td><strong>Developing and implementing a multifaceted intervention</strong></td>
<td>Five</td>
</tr>
<tr>
<td>PHASE 3</td>
<td><strong>Reflecting on the action</strong></td>
<td>Six</td>
</tr>
<tr>
<td></td>
<td>• Study E: Focus groups aged care staff</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Study F: Focus groups general practitioners</td>
<td></td>
</tr>
<tr>
<td>PHASE 4</td>
<td><strong>Measuring the impact of the action</strong></td>
<td>Seven</td>
</tr>
<tr>
<td></td>
<td>• Study G: Time 2, survey aged care staff</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Study H: Time 2, chart audit end-of-life care</td>
<td></td>
</tr>
<tr>
<td>PHASE 5</td>
<td><strong>Navigating a course for future action</strong></td>
<td>Eight</td>
</tr>
<tr>
<td></td>
<td>• Model of care development and recommendations</td>
<td></td>
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</tbody>
</table>

This thesis is composed of eight chapters which are aligned to the R-PAC Project’s action research phases. In Chapter One, the reader is introduced to the background, study aims and design of the R-PAC Project. In keeping with the dynamic nature of the action research process, the literature review related to each sub-study has been integrated into the relevant
Chapter Two describes the findings from Study A, a focused palliative care needs assessment which scopes and further defines the phenomena of interest for the R-PAC Project. In light of using mixed methods with action research, overall methodological, ethical and data considerations are discussed in Chapter Three. However, specific discrete elements related to each sub-study are reported in the relevant individual chapters. In some instances this may appear repetitive, but this strategy has been adopted to decrease ambiguity across the eight individual sub-studies.

The R-PAC Project’s five action research phases are integrated into Chapters Four to Eight. Chapter Four presents the data from three sub-studies undertaken to develop priorities for action and includes: Study B - pre-test chart audit; Study C - focus groups; and Study D - survey. The theory and literature guiding the development and implementation of the R-PAC Project’s multifaceted intervention is described in Chapter Five. Chapter Six is composed of two focus group studies reflecting on the intervention phase (Studies E and F). In Chapter Seven, the impact of the multifaceted intervention is further explored through the use of a survey (Study G) and a chart audit (Study H). In the final chapter, Chapter Eight, a course for navigating future action is outlined.

1.5 Significance of the R-PAC Project

Changes in demographic patterns and the burden of chronic illness have challenged palliative care clinicians to engage populations other than those with malignant disease\(^1\^3, 19, 20\). Managing the complex care needs of an ageing population is a global concern, especially given escalating health care costs and advances in medical science\(^21\). In Australia, it is estimated that 6% of over 65 year olds live in residential aged care facilities\(^22\). Since the collapsing of boundaries and merging of hostels and nursing homes\(^23\) as part of legislative reform\(^24\), the term ‘residential aged care facility’ has been used to describe regulated accommodation for older persons who require ongoing assistance with activities of daily living and nursing care\(^24\). This definition is interchangeable with the terms ‘convalescent home’, ‘aged care facility’ and ‘long-term care facility’\(^25\).

Most recently, both in Australia and internationally there has recently been a greater emphasis on community based care for the frail elderly\(^26, 27\). As a consequence, older persons residing in residential aged care are more likely to be those with dementia (60%), individuals experiencing chronic pain (40-50%) and residents who are depressed (40%)\(^28, 29\). Residential aged care facilities in Australia are increasingly becoming the place of death for many older
persons with approximately 20% dying within 12 months of being admitted to permanent care\textsuperscript{(22)}. Similar rates have been noted in the United States of America (USA) (24\%) and the United Kingdom (UK) (18\%)\textsuperscript{(30-32)}. Despite this burden of disability and death, the majority of older people dying in residential aged care will have their end-of-life care delivered by doctors, nurses and care assistants who are not palliative care specialists\textsuperscript{(33)}.

### 1.6 Changing paradigm for delivery of palliative care services

Specialist palliative care services have their genesis in oncology. In Australia, these services have evolved rapidly and are now well established, particularly in metropolitan areas. Specialist palliative care services predominantly care for adults with cancer, with approximately 85-90\% of all referrals being cancer related\textsuperscript{(34-36)}. It is widely accepted that people with non-malignant progressive disorders can also benefit from specialist palliative care input and that referrals to these services ought to be based on level of need\textsuperscript{(1, 36, 37)}. Advances in therapeutic approaches mean that the palliative phase of both malignant and non-malignant diseases is often longer and determining the terminal phase for some life limiting diseases is often difficult to predict due to the absence of reliable prognostic indicators\textsuperscript{(38)}. Whilst palliative care was formerly reserved for people who were dying, it is now acknowledged that this type of care is appropriate at any point in the course of a life limiting illness and can be provided in combination with life-prolonging treatment\textsuperscript{(39)}. The relevance of palliative care at various stages of a person’s illness trajectory is reflected in most contemporary palliative care definitions\textsuperscript{(35, 37, 40)}, including the current World Health Organisation (WHO) definition, which acknowledges that:

\begin{quote}
  Palliative care is an approach that improves the quality of life of patients 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\textsuperscript{(41)}.
\end{quote}

This revised definition is an important development as it confirms that palliative care is an ‘approach’ as opposed to a ‘service’. This change implicitly acknowledges the central role that all health care providers ought to play in delivering care, based on palliative principles, to people with progressive life limiting illnesses regardless of age, gender or location.
1.7 Equity in access to palliative care services

Access implies fairness\(^{(42)}\) and is a key component of all palliative care service delivery models. Accessing palliative care is a fundamental right for all Australians and is endorsed by government policy\(^{(35)}\). In keeping with the WHO definition and philosophy, access to services should not be determined by diagnosis or geographical location, but rather based on identified need\(^{(35, 37, 40, 43)}\). However, in Australia, the majority of specialist palliative care services remain attached to major metropolitan services, often with links to academia, and people living in rural and remote Australia are disadvantaged in respect to their access to specialist services\(^{(44)}\). The increasing demand for palliative care in regional, rural and remote areas, combined with the limited number of palliative care specialists and varying degrees of population size and isolation, presents considerable challenges for policy makers and health service planners\(^{(45, 46)}\). An examination of novel ways of extending the reach of palliative care to people with a progressive life limiting illness, including those in regional Australia, Indigenous Australians and older people in residential aged care is urgently required\(^{(40)}\).

1.8 Residential aged care: the last frontier for palliative care

Recent Australian research has investigated the palliative care needs of older people in residential aged care with non-malignant disease\(^{(47)}\), while another large collaborative study has developed guidelines for the delivery of a palliative approach in this sector\(^{(29)}\). These important studies have identified deficits in palliative care provision in this health care setting. However despite these advances, gaps remain in the literature as to how best to facilitate the adoption of a palliative approach within the aged care sector. In addition, there is limited knowledge of the palliative care competencies of nurses (registered and enrolled) and care assistants (unregulated workers) working in residential aged care. The Australian aged care setting is characterised by wide variations in workforce profiles, where typically large numbers of unregulated and untrained workers are employed to provide personal care, which is particularly challenging when palliative care demands a skilled nursing response\(^{(48)}\). There is a high staff turnover in aged care, which, in some instances, has resulting in an increased use of agency staff and little continuity of care\(^{(48, 49)}\). There is also limited knowledge available concerning the organisational and system characteristics necessary to facilitate the delivery of a palliative approach to care. This situation is not isolated to the aged care setting, with many areas of the health care system characterised by the dissonance between usual care and the best available evidence\(^{(50)}\). Reform within the Australian aged care sector has
traditionally been difficult to achieve due to the privatised nature of the industry, with significant change only occurring in response to legislation\(^49\). These characteristics suggest that facilitating a palliative approach to care for older people in residential aged care will present numerous challenges.

The R-PAC Project examines how a positive policy environment has impacted on promoting a palliative approach in the aged care sector in one regional Australian community. This project also explores how the local aged care teams responded to these policy changes and the degree to which this is translated into care practices. The mechanisms for delivering a palliative approach as perceived by residents, their families and the wider community is beyond the scope of the R-PAC Project, and remains a fertile area for future research.

1.9 Conclusion

The R-PAC Project is significant as the information derived from this study will add to the body of knowledge regarding the delivery of a palliative approach to older people in residential aged care, particularly in regional Australia. Of significance, this is the first study internationally to address a population based approach to palliative care within residential aged care in a regional setting. Encouragingly, all of the nine residential aged care facilities in Coffs Harbour elected to participate in the study. The findings derived from the R-PAC Project will detail important considerations relevant to health care planners and providers working in the palliative and aged care sectors not just in the local region but also nationally and internationally.

The following chapter will describe the role of needs assessment in health service planning and intervention development and the findings of a focused palliative care needs assessment. This preliminary investigation assisted in identifying the priorities for further actions.
1.10 Reference list


35. NSW Health Department. (2001). NSW Palliative Care Framework: A guide for the provision of palliative care in NSW.


47. Grbich, C., Maddocks, I., & Parker, D. (2003). *Palliative care in aged care facilities for residents with non-cancer diagnosis*. Adelaide: Department of Palliative and Supportive Services, School of Medicine, Flinders University.


Chapter 2.

*Increasing Access to a Palliative Approach in Residential Aged Care: A Focused Needs Assessment*
‘No journey carries one far unless, as it extends into the world around us, it goes on equal distance into the world within’

Lillian Smith

2.1 Introduction

Chapter One described the R-PAC Project and introduced the contextual issues facing care delivery for the older person in residential aged care. Yet, little is known about how to successfully address these care challenges. In order to develop and implement successful interventions, the requirements of local environments and consumers ought to be determined. Until the early 1980s, exploring the health needs and concerns of local communities had largely been ignored\(^1\). Since then, considerable effort has been directed towards recognising specific communities’ health needs through the process of conducting a systematic needs assessment. Contemporary approaches to needs assessments show scope for combining health and socio-demographic data with community opinion as a way of identifying foci for interventions and actively engaging the community\(^2,3\). A needs assessment is an invaluable planning tool that provides a framework for undertaking a systematic community analysis and diagnosis\(^3\). This process facilitates the assessment of the health needs of a population and helps determine the actual and potential level of service provision to address these needs. This chapter describes the methodological issues and findings of a focussed palliative care needs assessment of the Coffs Harbour community (Study A).

2.2 The role of needs assessments in health service planning

Within the health care sector a ‘need’ has been defined as ‘… what ever is required for health or comfort’\(^4\)(p.123). There are a range of health needs and the definition varies amongst disciplines, with clinicians, sociologists, health economists and epidemiologists all employing different operational definitions\(^5\). These definitions reflect the philosophical premises and perspectives of these professions.

An epidemiological approach to needs assessment defines ‘need’ in terms of the occurrence of specific diseases, meaning its distribution and health related states, rather than client groups\(^6\). Bradshaw’s\(^7\) typology however underpins a sociological approach to need, which suggests there are four types of needs: normative, expressed, comparative or felt needs. A normative need is what expert opinion defines as a ‘need’, such as immunisation schedules\(^8\). Even though this type of need governs a considerable amount of health planning, normative
standards often differ between groups and change over time\(^{(8, 9)}\). An expressed need is the inferences made about the health needs of a community by observing service utilisation\(^{(8)}\). However, if there are no services in the area then exploring expressed needs will be futile. A comparative need is defined by inferring that needs arising in one location can be deemed similar to those in another location, assuming that the population has comparable socio-demographic characteristics\(^{(8, 9)}\). A felt need is what the community identifies as a need, problem or concern that requires attention\(^{(8, 9)}\).

An economic approach is an alternative way of determining need. It is based on the premise that resources such as time, equipment, and people are all scarce and that consideration be given to their alternative uses in order to achieve optimal outcomes for the community as a whole\(^{(2, 5, 8-11)}\). Conducting a needs assessment without undertaking a comprehensive economic evaluation can lead to an inefficient use of resources, because there is little opportunity to compare alternatives, costs, and consequences\(^{(8, 12)}\). Incorporating the capacity for societal benefit into a needs assessment ensures that all proposed health interventions are considered from a cost and utility perspective. Underpinning this approach is an acknowledgment that the capacity to benefit is always going to be greater than available health care resources and that needs assessment should include some priority setting\(^{(8, 9)}\). Despite the focus on maximizing the impact of scarce resources, an economic approach to need has limited capacity to seek community input, consider community views and build community capacity\(^{(12)}\). This approach at times may be perceived to be unethical, particularly as value judgments are made about health priorities\(^{(12)}\). Further, this approaches unfamiliar terms can often alienate health care providers from engaging in the process\(^{(12)}\).

A needs assessment enables health care planners to systematically identify the gaps in local service provision and to identify what services are required to fill these gaps and the degree to which the proposed service(s) will be used by those in greatest need\(^{(5)}\). Obtaining high quality needs assessment data ensures that health care decision makers are provided with all of the relevant information, concerning health related needs, and possible solutions to enable planning and delivery of cost-effective services and initiatives\(^{(6, 11)}\). The needs assessment framework enables health care providers to navigate a pathway forward, while balancing the clinical, ethical and economic consideration of ‘need’; that is, what should be done, what can be done, and what can be afforded\(^{(13)}\). A needs assessment provides information to inform the objective and valid tailoring of health services and helps make certain that evidence underpins the commissioning of all new initiatives. This ensures that consideration is given to the
quality of the evidence relevant to the risks and benefits of specific interventions\textsuperscript{(14)}. Importantly a needs assessment can be the impetus that enables health care services to re-orientate care delivery from being institutionally focused to addressing populations needs\textsuperscript{(15)}.

\subsection*{2.2.1 Challenges of a needs assessment}

In spite of the benefits described above, a needs assessment has been described as an inexact science and several factors have been identified limiting its effectiveness\textsuperscript{(8, 11, 16)}. Significantly, health care providers often rely on intuition or anecdotal information to identify or address a particular problem as opposed to empirical research\textsuperscript{(8)}. A needs assessment implies that an inclusive process has been utilised to ensure that adequate consultation and input is received from a range of stakeholders. Yet local communities are often not involved in identifying, prioritising and responding to these needs\textsuperscript{(8)}. Importantly, a needs assessment process has the potential to create collaborative partnerships with the community. However when used inappropriately or without conviction it may be viewed as tokenism\textsuperscript{(8)}. Unfortunately, in some circumstances a needs assessments can become ritualistic and self-justifying especially if it is primarily focused on population demographics and the prevalence of specific problems, as opposed to facilitating health care reform\textsuperscript{(11, 16)}. Failure of the needs assessment process to identify and deal with factors that require institutions to change their practices can act to reinforce a potentially dysfunctional status quo in service or program delivery, rather than challenging services to change practices\textsuperscript{(8, 11)}. Although, undertaking a needs assessment implies that a change is required, there is little evidence determining documenting ‘need’ alone does in fact lead to effective health system change\textsuperscript{(13)}. If there is limited scope to facilitate change, then a needs assessment may be of little value. In spite of a commitment, many health services have limited capacity to re-orientate health priorities and funds into new programs without engaging in a range of far reaching reforms\textsuperscript{(17)}. Consequently, conducting a needs assessment without a commitment to implementing recommended solutions is a lost opportunity to address identified unmet need, resolve issues and an unnecessary and wasteful strain on scarce resources\textsuperscript{(17)}.

\subsection*{2.2.2 Specific challenges in palliative care needs assessments}

Increasingly, an economic approach is being utilised for health related needs assessments\textsuperscript{(8)}. However, this approach doesn’t always favour palliative care services, as palliation does not aim to save lives or increase life expectancy\textsuperscript{(17, 18)}. It could be argued that the quality of people’s lives is as morally significant as the number of lives which can be saved\textsuperscript{(13, 17)}. Three
types of needs assessment are predominantly used in palliative care, with the first being an epidemiological approach, which examines mortality from diseases likely to benefit from palliative care and links them to the type and frequency of symptom problems\textsuperscript{(17)}. The second approach evaluates evidence from patients receiving care in order to make an assessment of need\textsuperscript{(17, 18)}. The third method seeks to identify unmet need among those not receiving care\textsuperscript{(17)}. Regardless of the approach adopted, undertaking a comprehensive palliative care needs assessment is often challenging because it can place an additional burden on people with a life limiting illness, and their care givers, it can also be resource intensive\textsuperscript{(12)}. One way of addressing these challenges is to collect comprehensive needs assessment data from across a number of dimensions\textsuperscript{(11, 19)}. Therefore, a prospective, empirical approach is most likely to derive meaningful data. In spite of the challenges described above, prospectively outlining a methodological approach using systematic benefits can assist to overcome these challenges.

2.3 A focused needs assessment

As discussed above, needs assessment is a complex, multi-dimensional process\textsuperscript{(12)}. Adopting a focused approach to needs assessment\textsuperscript{(17)} is likely to be more efficient and effective as it is usually centered on: a particular specialty (e.g. mental health); a disease-specific group (e.g. people with diabetes); a client group (e.g. older people); groups waiting for interventions (e.g. people on waiting lists); vulnerable groups (e.g. ethnic minorities); or groups facing issues of inequity (e.g. isolated communities)\textsuperscript{(13)}. A focused needs assessment augmented by data from empirical research, the target population(s), service providers and decision makers can help to strengthen findings. It is important to ensure that a needs assessment is conducted as an iterative process and not as a ‘one-off activity’, but rather focussed on a targeted area of identified need\textsuperscript{(5, 8, 11, 13)}. This process is further strengthened by including key stakeholders on the research team as they can provide valuable insight into the variables relevant to identifying problems and potential solutions\textsuperscript{(5, 16, 19)}. A focused needs assessment helps prime the environment and offers the greatest potential for action because it occurs within the context of the health service committing to change. This approach deliberately seeks the input and views of the community on defined issues and/or problems which helps planners to anticipate where and how changes could occur in response to identified needs, which in turn, ensures desired outcomes are linked to a specific planning strategy\textsuperscript{(5)}.

An explicit framework is needed to plan the needs assessment process and make it manageable, allowing needs to be assessed in a systematic manner with priorities identified and changes made\textsuperscript{(8)}. Specific questions require a range of approaches and may involve a
combination of qualitative and quantitative research methods to collect original information, or adapt and apply existing data\textsuperscript{(4, 8)}.

2.3.1 \textit{Stages of a needs assessment}

A needs assessment can be divided into two distinct stages: i) identifying the priority health problem; and ii) analysing the problem\textsuperscript{(9)}. Identifying a number of worthy needs can make determining the health priority the most difficult stage of the needs assessment particularly as limited resources necessitate prioritisation. In determining which needs should be the focus of intervention, it is important to consider ‘…the prevalence, severity, selectivity, and likelihood that the problem will be amenable to change\textsuperscript{(8)}(p.474).’ A number of different criteria have been put forward to assist health care planners prioritise health problems such as: the burden or size of the problem, the number of people it affects; the cost to society; the degree to which the problem is selective or differential; whether it affects an already disadvantaged population subgroup; the severity of the problem in terms of the distress it causes; the degree to which the problem is amenable to intervention; the potential effectiveness of the intervention; the cost of the intervention compared to the benefits of the intervention; and whether anyone else is doing something about the problem\textsuperscript{(4, 20)}. Despite these being important criteria, the absence of an evaluation formula means that planners are still required to make quite subjective decisions about where to direct their health care resources. What is required, however, is a planning framework that can be used to guide the needs assessment process to determine the current state of affairs and integrate these criteria whilst using these data to design targeted interventions with the greatest potential to achieve the desired result\textsuperscript{(4)}.

2.4 \textit{The PRECEDE planning framework}

One potentially useful tool for undertaking a needs assessment is the five phase PRECEDE health education and planning framework developed by Green and Krueter in the 1980s\textsuperscript{(4, 21)}. PRECEDE is an acronym that stands for Predisposing, Reinforcing, and Enabling Constructs in Education, Diagnosis, and Evaluation\textsuperscript{(4)}. PRECEDE was subsequently expanded to capture environmental health factors influencing health and to include an evaluation component and become known as the PRECEDE-PROCEED framework\textsuperscript{(20)} (Figure 2-1). PROCEED is the second part of the framework and involves four phases that are focused on implementation and evaluation\textsuperscript{(4)}. These processes work in unison with the PRECEDE phases facilitating the
identification of priorities and the setting of objectives, while the PROCEDE phases assist in identifying the criteria for policy implementation and subsequent evaluation\(^4\).

The PRECEDE framework is based on the principles of epidemiology, the social, behavioural and educational sciences and health administration\(^4\). This eclectic method increases the utility of a needs assessment in the real world setting. Over the past two decades this framework has been used internationally by health care planners and researchers to design interventions that acknowledge a wide range of individual and environmental determinants of health\(^4\). Since then a large body of literature has been published regarding the successful application of PRECEDE in designing and implementing health care interventions\(^4\).

PRECEDE emphasises two fundamental propositions:

1. Health and health risks are caused by multiple factors; and
2. Efforts to effect behavioural, environmental, and social change must be multi-dimensional or multi-sectorial\(^21\).

As health care resources become more scarce there is a need to ensure the systematic and critical analysis of priorities and presumed causes is undertaken\(^22\). This planning framework takes into account the multiple factors that shape health status and assists health care planners to develop programs that intervene on factors that are both important and changeable, and encourages participatory research and practice\(^4, 22, 23\). A key attribute of the PRECEDE framework is that it directs health care planners to determine the desired outcomes at the commencing the planning process\(^4\). When one looks at the model (Figure 2-1), it is important to read from right to left, because the outcomes define subsequent phases.

The PRECEDE Framework, as shown in Figure 2-1, is a robust theoretical planning model that has been used in a variety of settings, including randomised clinical trials, field trials, by federal and state health departments, in the USA as a planning and evaluation tool\(^4, 24\). This prospective, goal directed planning is of great benefit in undertaking a focussed needs assessment. Five key diagnostic phases comprise the PRECEDE framework: i) social; ii) epidemiological; iii) behavioural and environmental; iv) educational and organisational; and v) administrative and policy.
2.4.1 Social diagnosis

In the PRECEDE Framework the planning process commences with a Social Diagnosis (Phase 1) of the target population which involves assessing their general hopes, problems or concerns as indicators of their quality of life\(^4\). The problems and priorities of individuals or communities are defined through the active engagement of the target population, which is critical to achieving the desired change. This principle is shaped by the community development root theories and Freire’s empowerment education model\(^{4, 24, 25}\). Acknowledging this theoretical construct ensures that priorities are not imposed by health care planners, rather the active engagement of participants. Adopting a collaborative approach assists with assessing perceived problem(s), identifying unique needs and aspirations, preference for dealing with these problems and the generating of consensus\(^4\). The aim of this phase is to specifically identify and evaluate the social problems which impact on the quality of life of the target population.
Multiple sources of data collection such as key informant interviews, community forums, focus groups, nominal group processes, survey social indicators, and archival research, augmented with national, state, and local health indicators of the target population need to be considered during this phase. Undertaking this process assists in gaining a perception of the situation from the stakeholders perspective. Programming priorities and the effective allocation of scarce health resources are generally based on a thorough analysis of the data indicating the pervasive nature of the problems and their human and economic cost. Establishing a link between these problems and the target population helps to start focus the planning process. During this phase, a set of clearly defined program objectives is developed, which will ultimately assist with the evaluation process.

2.4.2 Epidemiological diagnosis

During the Epidemiological Diagnosis phase (Phase 2) the focus is on identifying the specific health goals or problems that may contribute to the target populations’ quality of life, social goals or problems noted in the Social Diagnosis (Phase 1). All available epidemiological data, medical findings, and information generated by appropriate investigations assist in identification and description of various health problems of importance to the target population. This process helps to identify the behavioural and environmental factors that impact on the target population’s quality of life by mapping the relationship between health problems and quality of life. The epidemiological assessment identifies those health problems and their risk factors that deserve priority based on their importance and changeability. The use of a ranking process helps to determine the relative importance of each health problem. This is achieved by ranking both the importance of the health problem in the target population and the potential for an intervention to impact positively. In applying this formula it is also helpful to identify the issue most amenable to intervention, which is referred to as ‘changeability’. There are a number of questions that can assist with interrogating the data.

The epidemiological diagnosis process leads to the setting of priorities and guides the focus of health intervention development and resource utilisation. It also assists with delineation of responsibility of those professionals and organisations involved in the health program. The completion of this phase ensures determining health priorities and establishing program objectives to be achieved.
Table 2-1: Potential Epidemiological Diagnosis questions

<table>
<thead>
<tr>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which problem has the greatest impact in terms of death, disease, days lost from work, rehabilitation costs, disability, family disorganisation, and cost to communities and agencies for damage repair loss and cost recovery?</td>
</tr>
<tr>
<td>Are certain sub populations most at risk?</td>
</tr>
<tr>
<td>Which problem is most susceptible to intervention?</td>
</tr>
<tr>
<td>Which problem is not being addressed by other agencies in the community?</td>
</tr>
<tr>
<td>Is there a need that is being neglected?</td>
</tr>
<tr>
<td>Which problem, when appropriately addressed, has the greatest potential for an attractive yield in improved health status, economic savings, or other benefits?</td>
</tr>
<tr>
<td>Are any of the health problems considered to be a regional or national priority?</td>
</tr>
</tbody>
</table>

Source: Green and Kreuter (4) (p.209)

2.4.3 Behavioural and environmental diagnosis

During the Behavioural and Environmental Diagnosis phase (Phase 3) of the planning process, all behavioural and non-behavioural causes (personal and environmental factors) that could be contributing to the recognised health problem are identified and considered (27). Non-behavioural causes include diverse factors such as age, gender, genetics, existing diseases, climate, workplace and adequacy of existing health care services (26). Previous research has identified a multitude of environmental factors that act as barriers to innovations in the health care setting including: a lack of time and energy and resources, a lack of multidisciplinary team work, the reluctance to change, an unstable workforce and the lack of a supportive organisational culture (26). Behavioural diagnosis involves an analysis of all of the behavioural links to the goals or problem that have been identified. The use of a matrix helps to identify targets where the interventions are likely to have the most impact, based on importance and changeability (Table 2-2). As a general rule, behavioural objectives are created from Quadrant I and II, while Quadrant III is used to demonstrate organisational achievement or when there is a political or organisational reason to document change (4).
Table 2-2: Behavioural matrix to assist with targeting interventions

<table>
<thead>
<tr>
<th>MORE CHANGEABLE</th>
<th>MORE IMPORTANT</th>
<th>LESS IMPORTANT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HIGH PRIORITY</td>
<td>LOW PRIORITY</td>
</tr>
<tr>
<td>Quadrant I</td>
<td></td>
<td>Quadrant III</td>
</tr>
<tr>
<td>LESS CHANGEABLE</td>
<td>PRIORITY FOR INTERVENTION</td>
<td>NO INTERVENTION</td>
</tr>
<tr>
<td>Quadrant II</td>
<td></td>
<td>Quadrant IV</td>
</tr>
</tbody>
</table>

Source: Green and Kreuter (4) (p.140)

2.4.4 Educational and organisational diagnosis

During the Educational and Organisational Diagnosis phase (Phase 4) all possible predisposing, reinforcing and enabling factors are identified and considered (4). *Predisposing Factors* include a person’s knowledge, attitudes, beliefs, values, and perceptions that facilitate or hinder motivation to change (4). *Enabling Factors* are those skills resources, or barriers that can help or hinder the desired behavioural or environmental changes. Essentially they are all the things that make a desired change in behaviour possible, such as the characteristics of an environment to facilitate action and any skill or resource required to attain a specific behaviour (4). *Reinforcing Factors* are the rewards and feedback received following adopting a behaviour, which may encourage or discourage an unwanted behaviour. This reinforcement often comes from family, peers and teachers (4). The critical step in this phase is to identify and select those factors most likely to result in behavioural change as a result of the intervention. Ranking their relative importance and potential for change is a critical step in this phase. Acknowledging the resources available to facilitate the desired change, their accessibility, plus the skills required helps to ensure that the highest ranked factors become the focus of the targeted intervention (26).

2.4.5 Administrative and policy diagnosis

Administrative and Policy Diagnosis phase (Phases 5) allows for an assessment of the organisational and administrative capabilities and resources required for the development and implementation of an intervention to be considered (28). Undertaking this step ensures that the policy, resources and organisation of factors that could hinder or facilitate the development of the intervention are all taken account in the analysis. In addition, it is important to ensure that
the organisation’s mission and goals are compatible with the goals and objectives of the intervention\textsuperscript{(29)}.

2.5 \textit{Method adopted for the R-PAC Project needs assessment}

This needs assessment undertaken as part of the R-PAC Project has been informed by the conceptual needs assessment literature, previously described and the PRECEDE Framework\textsuperscript{(4)}. This framework was adopted as it was considered it would aid in assessing population needs, whilst guiding the development of targeted strategies to address the identified gaps. It helped focus attention on those issues of highest importance and those most amendable to change, ensuring the most effective use of scarce health care resources\textsuperscript{(4)}.

2.6 \textit{Description of the regional community of Coffs Harbour}

Coffs Harbour is a coastal community on the Mid North Coast of New South Wales (NSW) Australia, that is located half way between Sydney in the south and Brisbane to the north. The Coffs Harbour LGA has a population of approximately 67 000 people, with the largest concentrated population residing in the suburbs of Coffs Harbour\textsuperscript{(30)} (Figure 2-2). The remaining population is located in smaller coastal townships, which are popular holiday and retirement destinations, or in adjacent inland farming communities\textsuperscript{(28)}. The area boasts a relaxed lifestyle and over the past 20 years has had the highest population growth in NSW, with an annual growth rate of 2.3%, primarily due to the internal migration of over 65 year olds\textsuperscript{(31)}. This population group constitutes 16.8\% of the Mid North Coast population compared with only 12.9\% of the population nationally\textsuperscript{(28)}.
Within the region, transport infrastructure is poor with limited access to community based services targeting the elderly\(^{(28)}\). The LGA’s Index of Relative Socio-Economic Disadvantage, a score developed by the Australian Bureau of Statistics is 948\(^{(28, 29)}\). This score is 5.2% lower than the average for Australia (1000), and lower than that of country NSW (973)\(^{(28, 29)}\). This score highlights the lower socioeconomic status profile of the Mid North Coast’s population, relative to Australia as a whole\(^{(28)}\). Illustrating this, a quarter (25.3%) of all households receive rent assistance\(^{(33)}\). Further, this lower socioeconomic profile is thought to be linked to the areas higher incidence of serious health issues. These are related to a range of chronic diseases and higher health risk factors, such as obesity, smoking and physical inactivity\(^{(28, 30, 31, 34)}\).

In addition to the lower socioeconomic status profile, the area has a large Indigenous population, representing about 3.2% of the local population, compared with the average of 1.9% across NSW\(^{(28)}\). Of note, the Mid North Coast is home to a well established Punjabi community located at Woolgoolga\(^{(28)}\). Both Indigenous and Punjabi peoples are noted for an increased incidence of chronic and complex diseases and lifestyle risk factors compared to the general population\(^{(28)}\). Despite these pockets of cultural diversity, there is predominance of
Australians of Anglo-Celtic and European origin with overseas born people representing only 9.2% of the area’s population, which is well below the Australian average of 27.4%\(^{(28, 35)}\).

### 2.7 Key challenges to palliative care services

An extensive review of local epidemiological data and reports\(^{(28, 30, 34)}\) has identified a range of factors challenging the delivery of palliative care services on the Mid North Coast, including: population ageing, burden of chronic diseases, increased demand for palliative care services, absence of quarantined palliative care beds, increased demand from residential aged care, and workforce issues.

#### 2.7.1 Population ageing

It is anticipated that the popularity of the Mid North Coast as a preferred retirement destination for baby boomers will continue, with 35% of population growth expected to be in the over 65 age group by 2031\(^{(31)}\). By this time, it is anticipated that this area will have the highest proportion of over 65 year olds in NSW. Mid-way through this period, the number of deaths within the population are expected to exceed the number of births\(^{(28, 36, 37)}\) (Figure 2-3).

![Graph showing population projections](image-url)

*Source: Rowland, D. Coffs Harbour Cohort Projection Model\(^{(38)}\)*

**Figure 2-3:** Coffs Harbour population 2001 (shaded) and projections for 2011
For some retirees, their new lifestyle is accompanied with disability and decline. This is particularly challenging for those who have relocated to the area and have minimal or no local family support and are dependent upon community based services that are already under significant pressure\(^{(39)}\). Most retirees are dependent upon an aged pension and often lack the funds to purchase additional private health care services\(^{(30, 31)}\). The health care and support services required by older people in Coffs Harbour are likely to vary considerably. From a palliative care perspective, living alone combined with no primary care giver is a strong predictor of increased hospitalisations for symptom control and/or end-of-life care\(^{(40)}\).

In 2003, 7.7% of local over 65 year olds lived in residential aged care facilities\(^{(39)}\), which is higher than the current Australian estimates of 6%\(^{(41)}\). The profile of people admitted to aged care facilities in Australia is changing, with almost half (49%) having lived alone immediately prior to admission, nearly three quarters (72%) of all new residents are female, and half (52%) of all new residents are aged over 85 years\(^{(41)}\). In Australia, the number of residents requiring high level care has increased from 58% in 1998 to 67% in 2005\(^{(41)}\). This maybe related to application of this new term ‘high level care’ as part of the introduction of the Residential Classification Scale (RCS), a funding tool introduced in 1997 as part of the aged care reform\(^{(42, 43)}\). Alternatively the increase in numbers of residents with high care needs may reflect that increasingly older people admitted to Australian aged care facilities have a higher burden of complex conditions, co-morbidities and higher rates of disability than the general aged population, resulting in high levels of dependency\(^{(44)}\).

### 2.7.2 Paradoxical population shifts

At the same time, Coffs Harbour LGA is experiencing an influx of retirees there is also a significant outward migration of younger people, who potentially comprise the health care workforce\(^{(45)}\). This shift is contributing to a shortage of nurses locally, which mirrors the national and global phenomena\(^{(46)}\). Of concern is the projection that there will be insufficient people of working age to provide health care and social support to the local ageing population in the near future (Figure 2-3)\(^{(28)}\). In addition, a shortage of general practitioners, medical specialists and nurses have already been noted in the region\(^{(30)}\). A limited supply of health care providers impacts on the community’s ability to access timely medical support.
2.7.3 Burden of chronic disease

The term chronic disease encapsulates a range of health problems that persist across time and require some degree of health management\(^{(28)}\). Chronic disease tends to increase with age, have complex causes and produce a range of complications, the effects of which exist for a prolonged period. The Mid North Coast has generally higher rates of respiratory, cardiovascular and musculoskeletal disease and Type II diabetes than Australia as a whole\(^{(28, 35)}\). The major causes of premature mortality in the area, as for country NSW and Australia, are due to cancer and diseases of the circulatory system\(^{(35)}\). The higher rates for risk factors such as being overweight, obesity, smoking and physical inactivity are likely explained by regions lower socioeconomic status and Indigenous profile\(^{(35, 47)}\). As a result, chronic diseases are responsible for a significant burden of disease and illness in this community. Despite there being an increased focus on healthy ageing, growing older continues to be associated with the onset of chronic, and for many, potentially progressive life limiting illnesses\(^{(48)}\).

2.7.4 Existing palliative care service model

The Coffs Harbour palliative care service, based at the local regional hospital, was one of the earliest rural services in NSW, commencing operation in 1984, and has been previously described as a ‘…sound example of a community based service’\(^{(47)}\)(p.71). This service provides seven day per week specialist nursing coverage. The team works collaboratively with local general practitioners to coordinate and deliver community based palliative care. There is limited community nursing input into the delivery of palliative care in Coffs Harbour\(^{(39)}\). The palliative care service has a designated part-time social worker, trained volunteers, a visiting palliative care physician service, access to hospital based allied health personnel, a large loan equipment pool and a bereavement support program\(^{(39)}\). The palliative care service has strong links with locally based oncology, renal, neurology and cardiology services and other clinical experts\(^{(39)}\).

Although the number of specialist palliative care nurses based in Coffs Harbour has increased from 1.5 Full Time Equivalents (FTE) in 1984 to the current 5 FTE, the service now covers a significantly larger geographic area encompassing two LGA’s\(^{(39)}\). Additionally, the number of patients referred to the service has increased from approximately 50 referrals in 1984 to 240 referrals in 2003\(^{(39)}\). In 2003, it was estimated that, on any given day, over 110 palliative care patients were registered with the local specialist palliative care services\(^{(39)}\). Similar to
other Australian palliative care services, symptom control is the primary reason for admission to the local service, followed by terminal care\(^{(47, 49)}\).

Community based services have frequently provided care for extended periods of time as a consequence of the prolonged illness trajectories of many chronic and complex conditions\(^{(50-52)}\). However, these community based supports are often inadequate to meet the care needs of people dying from a life limiting illness and the majority (60\%) of patients admitted to the specialist palliative care service during 2003 received their end-of-life care in an acute care setting\(^{(39)}\). Given the regions aged population profile this figure may also reflect the lack of a full-time care giver or inability of a care giver to meet the intense and sustained demands of caring for a dying family member in the community setting. Despite these end-of-life hospitalisation rates, there are no designated in-patient palliative care beds in Coffs Harbour. People requiring in-patient palliative care are admitted to either the local base or private hospitals for symptom management and/or end-of-life care. Without a substantial increase in community based supports, it is unlikely that this rate will fall and the acute care sector will be required to deliver palliative care on a continuing basis. A recent planning framework has estimated that 6.7 designated palliative care beds are required per 100 000 population\(^{(51)}\), which approximates to 4.5 palliative care beds required locally\(^{(39)}\). This metric has implications for the configuration of local acute bed allocations and staff patient ratios in the acute care sector.

### 2.7.5 Increased demand from residential aged care

The high service demands placed on the local palliative care service means that there have been very limited opportunities to provide input, education and consultancy to the nine local residential aged care facilities. When the R-PAC Project began in 2004 these local aged care facilities were collectively providing care to 598 older people\(^{(39)}\). Increasingly these aged care beds are being occupied by the chronically unwell, frail aged and in many respects function as slow stream hospices for people with non-malignant disease\(^{(53-55)}\). Clearly, many older people with progressive life limiting illnesses, are admitted to these facilities with the knowledge that they will die in this setting which makes it impossible to ignore end-of-life planning.

Chronic, progressive life limiting illnesses tend to follow one of three illness trajectories (Figure 2-4)\(^{(56)}\). As shown in Figure 2-4, people with cancer tend to have a more predictable decline, with significant disability often only occurring in the last weeks of life (Trajectory A)\(^{(56)}\). However the majority of older people living in aged care settings tend to die of
complications from non-malignant diseases, either related to progressive organ failure or advanced dementia\(^{(49, 57, 58)}\). Those with organ failure, such as heart failure or chronic obstructive pulmonary disease, usually live for an extended period of time following their diagnosis. Their disease course tends to be punctuated by periods of acute exacerbation and remissions of symptoms\(^{(56)}\), with the timing of death being somewhat unpredictable (Trajectory B)\(^{(56)}\). Persons with dementia or who are generally frail usually have a protracted decline prior to death. For these people death may not occur for many years after their diagnosis, with the ability to self care lost often many years before they die (Trajectory C)\(^{(56)}\).

As part of the needs assessment, data relating to deaths in the nine residential aged care facilities in Coffs Harbour during 2003 were examined. During this 12 month period there were 169 deaths, with the majority of residents (\(n=133; 79\%\)) dying in the aged care facility\(^{(39)}\). A review of workforce data showed that dying residents were largely cared for by care assistants (\(n=284, 71\%\)) or unregulated workers who were supervised by a smaller number of registered nurses (\(n=78, 20\%\)). As is the case nationally, local aged care facilities employ a very small number of enrolled nurses (\(n=36, 9\%\))\(^{(60)}\). All on-site medical care was provided by the residents’ general practitioner\(^{(61)}\). A shortage of local general practitioners means that it is often difficult to obtain timely medical review for residents\(^{(55)}\). Of significance to the R-PAC Project, the policy of the local aged care facilities identifies that if the resident requires a medical assessment and the general practitioner is unavailable, the

![Figure 2-4: General trajectories of function and well-being over time in eventually fatal chronic illnesses](image-url)

Source: Adapted from Lynn, J.\(^{(59)}\) (p 930)

Figure 2-4: General trajectories of function and well-being over time in eventually fatal chronic illnesses
dying resident is to be transferred by ambulance to the Emergency Department at Coffs Harbour Health Campus.

2.7.6 **Health workforce shortages**

Despite the Mid North Coast being an idyllic rural location, it has become increasingly difficult to attract skilled medical and nursing workforce to Coffs Harbour\(^{(55)}\). The local Division of General Practice conservatively estimates that the area is in need of a dozen more general practitioners in order to meet the recommended number given the size of the population\(^{(55)}\). Workload issues and geographical distances in a regional community make it difficult for many general practitioners to respond in a timely manner to people in need and very few provide after-hours care or conduct home visits\(^{(49, 62)}\). Previous Australian research had identified that there was limited systematic coordination of general practitioner input and participation into the management of people receiving palliative care in the community or in aged care facilities\(^{(61, 63)}\). Interviews and case note examination of hospital, palliative care and residential aged care clinical records revealed that locally medical input is primarily reactive as opposed to being proactive and adopting systematic care planning. Time constraints and the lack of financial reward are the reasons anecdotally provided by local general practitioners for not conducting home visits, including regular visits to residential aged care facilities\(^{(64)}\).

2.7.7 **Information systems and data collection**

Throughout Australia there is considerable disparity in palliative care data collection with different services using various definitions and data items. Current data collection methods are primarily paper based or link to acute hospital electronic data bases. As a consequence, there is an inadequate description of service provision and consumer needs\(^{(39)}\). The Australian National Sub-Acute and Non-Acute National Case-mix Classification Study (AN-SNAP) identified a five-phase classification system for palliative care that is independent of the setting and is sensitive to changes in the goal of care\(^{(65)}\). However, this data collection system has yet to been implemented locally, which makes it difficult to accurately determine and map local palliative care service need\(^{(65)}\).

2.8 **Facilitators to service delivery**

In spite of the challenges listed above, several local factors exist to drive the improvement of palliative care service delivery in Coffs Harbour.
2.8.1 *Health facilities and services*

Coffs Harbour is home to the area’s major referral hospital, providing a broad range of specialty services consistent with a Level 5 Base Hospital as well as an 80 bed private hospital\(^{31,39,42}\). A purpose built Cancer Care Centre with a radiotherapy unit and one linear accelerator was commissioned during the course of the R-PAC Project and commenced operation in mid 2007\(^{39}\). The number of aged care beds in Coffs Harbour has also been significantly expanded as a result of increasing demand and community pressure, with the numbers now within established planning ratios to meet anticipated local need\(^{39}\).

2.8.2 *Community participation*

The local palliative care service benefits from significant local community support which has ensured the acquisition of a large loan equipment pool through donated funds. The palliative care volunteers consist of interested local community members who have undertaken appropriate training and are provided with ongoing supervision and support. A voluntary organisation assists cancer patients requiring out of area medical treatment and provides accommodation and support for families in a purpose built lodge at Coffs Harbour Health Campus. A branch of the National Association of Loss and Grief (NALAG) has recently been established and a local financial institution has funded an aged care academic position to focus on aged care issues pertinent to rural and regional Australia\(^ {66}\). These initiatives all suggest that there is considerable community support for the continued enhancement of local palliative and aged care services.

2.8.3 *Expansion of locally available education services*

A tertiary education facility has been established at Coffs Harbour with the first intake of local Bachelor of Nursing students occurring in 2004, while Tertiary and Further Education (TAFE) conducts enrolled nursing and care assistant courses. An undergraduate medical student program with an on-site campus located at Coffs Harbour Health Campus has recently been established. It is anticipated that these locally based initiatives will improve workforce shortages in the area and better prepare health care providers to work within regional communities.
2.9 **Positive policy environment**

As a part of a focused systematic needs assessment, it is important to consider the policy framework, particularly within the context of universal health care coverage within Australia. Australian public policy acknowledges that access to palliative care is a right for all people with a progressive life limiting illness, this philosophy is reflected in a range of key policy documents, leadership and funding initiatives\(^{(57, 61, 63, 67, 68)}\).

2.9.1 **Australia’s National Palliative Care Strategy**

The National Palliative Care Strategy provides a guide for the development and implementation of palliative care policies, strategies and services to improve the quality, range and coverage of palliative care\(^{(67)}\). A total of $201.2 million has been allocated to palliative care, throughout the five years of the Australian Health Care Agreement (2003 - 2008), with one of the priorities being to increase the range and reach of palliative care\(^{(65)}\). This policy is responsive to perceived service delivery deficits and inequity of access to palliative care. The National Rural Palliative Care Program is an example of the Commonwealth Governments commitment to making palliative care available to these in need of this type of care, regardless of location\(^{(67)}\).

**National Rural Palliative Care Program**

The National Rural Palliative Care Program aims to improve access to quality coordinated palliative care for people living in rural and remote communities by strengthening local care partnerships\(^{(68)}\). This initiative is addressing clinical governance and management, direct care delivery, professional participation, management and use of patient information, and evaluation, data collection, and reporting\(^{(17)}\). Gaining National Rural Palliative Care Program funding, of $600,000 through a competitive process over three years by the Mid North Coast Division of General Practice, has provided a unique opportunity to address this community’s palliative care deficits\(^{(68)}\).

2.9.2 **NSW Palliative Care Framework**

The NSW Palliative Care Framework\(^{(69)}\) builds upon the concepts enunciated in the National Palliative Care Strategy to identify a number of key elements that aim to promote access, continuity of care and standard levels of care, regardless of the location in which the service is provided. In NSW, the majority of funding for palliative care is provided by the State
government, in accordance with the resource distribution formula and it is the responsibility of each Area Health Service to determine how palliative care is provided locally\textsuperscript{(70)}. Although in 2001, all NSW Area Health Services were requested to prepare an Area Palliative Care Services Plan in accordance with accepted palliative care frameworks\textsuperscript{(67, 69, 70)} and standards\textsuperscript{(51)}, little is known about the degree to which these plans have been actioned.

### 2.9.3 Palliative Care Australia

Since 2003, Palliative Care Australia, the peak non-government organisation for palliative care has released three significant policy documents. These policies provide guidance for the developing of palliative care services at a national, state, regional and local level. A ‘Guide to palliative care service development: a population based approach’\textsuperscript{(69)} provides a framework to ensure the equitable access to palliative care for all Australians based on the efficient, effective, and ethical use of resources. ‘Palliative care service provision in Australia – a planning guide’\textsuperscript{(51)} provides a formula for determining the human resources needed for the provision of specialist palliative care services in Australia. The ‘Standards for providing quality palliative cares for all Australians’\textsuperscript{(71)} is a tool integral for the planning and delivery of a coordinated network approach to palliative care provided by both primary and specialist service providers\textsuperscript{(69)}. Collectively these platform policy documents provide a clear framework and guidance for the development of palliative care services throughout Australia.

### 2.9.4 A population based approach to service delivery

There are potentially three broad sub-groups of people whose progressive, life limiting illness acuity and complexity will define the level of specialist palliative care input required (Figure 2-5)\textsuperscript{(72)}. The vast majority (Group A) of the palliative care populations’ care needs will be adequately met by their primary care providers. These care plans may involve family members, community nurses, general practitioner and medical specialist’s services such as oncology, neurology and cardiology. People who experience occasional or sporadic exacerbations of physical, psychological or social problems (Group B) will require expert consultation from a specialist palliative care service, with their ongoing care continuing to be provided by their primary care provider. Within this group there is a subgroup of people with more intense care needs that will be best serviced by a shared care arrangement between primary provider and specialist palliative care service.
The smallest sub group of palliative care patients (Group C) will have complex care needs that have not responded to established care protocols and require ongoing involvement from a specialist palliative care service. Specialists will be required to work in partnership with primary care providers to develop and implement an appropriate care plan to specifically address individual patient needs\(^{(73-78)}\). It is expected that some patients’ needs will change over time requiring them to move between different levels of care. In addition to this delineation in service delivery, of greater significance has been the adoption of a palliative approach to care. This approach is integrated across the illness trajectory and is not confined to terminal care, which is a common misconception among health professionals and consumers relating to palliative care services. These attitudes and beliefs have particular implications for palliative care in residential aged care.

### 2.9.5 Emergence of a palliative approach

As discussed above, residential aged care facilities are increasingly the place of death for older people and could now be seen as slow stream hospices in marked contrast to their previous focus on rehabilitation and convalescence\(^{(55)}\). Previous research has identified numerous obstacles to providing palliative care in residential aged care, including: inadequate staffing levels; a regulatory focus on rehabilitation; a lack of palliative care competencies; the
failure to recognise treatment futility, a lack of communication amongst decision makers, residents and families regarding end-of-life issues, and a failure to implement a timely end-of-life care plan\(^{(57, 73, 74, 78-80)}\). A more recent study has identified structural barriers that operate within aged care and impact adversely on the quality of pain management and end-of-life care\(^{(81)}\).

In Australia, the burden of disability and death in residential aged care facilities has prompted the development of evidence-based guidelines\(^{(57)}\), recommending that aged care providers integrate a palliative approach into their organisational practice\(^{(82, 83)}\). These guidelines identify three pathways for integrating the delivery of needs based palliative care for older people in residential aged care. The first pathway focuses on the delivery of a palliative approach as a way of improving the quality of life for people with a progressive life limiting illness and their families\(^{(57)}\). A palliative approach focuses on reducing suffering through early identification, assessment and treatment of pain, as well as other physical, psychological, social and spiritual needs\(^{(57)}\). This philosophy ought to underpin all care provided to older people in residential aged care because it focuses care on improving quality of life, promoting symptom control, dignity, and comfort for the older person, whilst acknowledges the needs of families\(^{(57)}\). The second pathway identifies that in addition to an integrated palliative approach, a proportion of residents with complex symptom management needs, will require access to expert specialist palliative care in-put\(^{(57)}\). The third pathway identifies that end-of-life care is reserved for residents who are imminently dying\(^{(84)}\). Importantly, these guidelines reinforce the need for a palliative approach throughout an older person’s residential care trajectory, rather than merely restricting the focus to terminal care\(^{(85)}\). This requires a level of organisational and health care provider reform.

### 2.10 Applying the PRECEDE framework to identify the priorities

A wide range of health care needs have been identified during the focused palliative care needs assessment undertaken in the Coffs Harbour LGA. To assist with the identification of priorities the needs assessment data has been applied to the PRECEDE framework. The findings from Phase One to Three of PRECEDE are detailed in the next section.

#### 2.10.1 Phase One: Quality of life

A review of the literature, local policy documents and key informant interviews determined that optimal outcomes for palliative care patients and their families were not always achieved.
Based on these data and using the PRECEDE framework, an overall goal for local palliative care delivery in Coffs Harbour was determined:

That older people with progressive life limiting illnesses and their carers who reside in the Coffs Harbour local government area require access to best evidence based palliative care practice and accepted standards by December 2006.

2.10.2 Phase Two: Epidemiological diagnosis

Incidence and prevalence do not necessarily equate with need, but they are both important in describing a population burden of disease\(^6\). Consequently all epidemiological data relevant to the Coffs Harbour LGA was examined including: local population data (age, sex, ethnicity and socioeconomic status); local information on total mortality or mortality from specific causes; local morbidity data and hospital activity data\(^{28, 30, 34, 86}\). These data reveals that people over 65 years of age are most affected by chronic and complex diseases, many of which are progressive life limiting illnesses which inevitably lead to death\(^{28}\) (Table 2-3). The population growth of over 65 year olds in Coffs Harbour, affected by chronic and complex health problems, is likely to continue to increase and has the potential to impact significantly on the delivery of palliative care services\(^{57}\). These epidemiological data lead to the development of the following palliative care program objective:

That people over 65 years of age, who reside in the Coffs Harbour local government area and who have a progressive life limiting illness will have access to an appropriate level of palliative care, in accordance with their individual need(s), by December 2006.

2.10.3 Phase Three: Behavioural and environmental diagnosis

There are a range of behavioural and environmental factors impacting on the delivery of palliative care to older people with a progressive life limiting illness residing in Coffs Harbour. Applying the PRECEDE Framework ranking formula has revealed the environmental factors that are most important and most amenable to change, which is referred to in the Tables as ‘changeability’ (Table 2-4). Care needs in excess of available community services and lack of a full-time carer are some of the most probable reasons older people are
admitted to the acute or residential care settings. Older people are most likely to die from complications associated with a chronic and complex disease in either the acute hospital or in a residential setting. As a consequence there is a need to ensure that older people in Coffs Harbour have access to best evidence based end-of-life care.

Table 2-3: Epidemiological diagnosis

<table>
<thead>
<tr>
<th>Health Problems</th>
<th>Importance</th>
<th>Changeability</th>
<th>Total</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality due to cancer</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Mortality due to cardiovascular disease</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Mortality due to pulmonary disease</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Mortality due to renal disease</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Mortality due to neurological diseases</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Mortality due to other organ failure</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Mortality due to ageing process</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Age related morbidity and co-morbidities</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Significant population growth</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Increased inward migration of over 65 year olds from inland NSW and Sydney</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Indigenous population</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Punjabi population</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

Key: Low = 1, Medium = 2, High = 3

The behavioural factors impacting on the delivery of palliative care to older people and the application of the PRECEDE-PROCEED ranking formula are detailed in Table 2-5. The needs assessment revealed limited numbers of referrals to the specialist palliative care team to review residents, including those with non-malignant disease. At the time of the assessment, the specialist palliative care team had not provided any palliative care education to local residential aged care settings. Similar to other parts of the developed world, aged care nurses are unlikely to have specialist palliative care training\(^{(5, 16, 19)}\). Considering behavioural factors
and applying the PRECEDE ranking formula has helped to identify those factors most amenable to change. Key factors relate to enhancing the level of palliative care support provided to local residential aged care providers and ensuring that palliative care is accessible by those who have a progressive and life limiting disease of a non-malignant origin.

**Table 2-4: Environmental diagnosis**

<table>
<thead>
<tr>
<th>Environmental Factors</th>
<th>Importance</th>
<th>Changeability</th>
<th>Total</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths in acute hospitals</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Deaths in residential aged care facilities</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Deaths at home</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Limited access to palliative care physician</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Limited access to General Practitioner</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>No after-hours palliative care service</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>No access to designated palliative care beds</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>No local hospice</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Access to a specialist palliative care team</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Limited access to assistance with hygiene</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Access to a full time competent carer at home</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Limited access to family support and/or absence primary care giver</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Limited income – aged pension</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Limited access to public transport</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Limited access to residential aged care facilities bed</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

Key: Low = 1, Medium = 2, High = 3
Table 2-5: Behavioural factors

<table>
<thead>
<tr>
<th>Behavioural Factors</th>
<th>Importance</th>
<th>Changeability</th>
<th>Total</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited referrals to specialist palliative care team from residential aged care facilities</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Limited palliative care education in residential aged care facilities</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Limited number of residential aged care facilities nurses who have undertaken palliative care training and/or education</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Limited number of referrals to specialist palliative care team for patients with a non-malignant disease</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Difficulty accessing timely medical assessment resulting in residents being transferred to emergency</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Family requesting residents be transferred to the acute care setting</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Limited referrals to visiting palliative care physician</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Limited number of GPs visiting residential aged care facilities</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Limited number of GPs who bulk bill</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

Key: Low = 1, Medium = 2, High = 3

These factors combined with a positive policy environment promoting the delivery of a palliative approach to older people in aged care settings,\(^{(87, 88)}\) suggested that focusing on enhancing the palliative care needs of older people in residential aged care was required. In applying the PRECEDE framework it was considered that this factor was not only of significance but that positive changes could be achieved within the project funding timelines. Focusing on this identified need would help to ensure that all older people who reside in Coffs Harbour residential aged care facilities have were provided with a palliative approach to care by December 2006.
2.11 Conclusion

A needs assessment represents a synthesis of epidemiological, social science perspectives, economic considerations, community opinions and values that empirically inform a strategic plan to inform service delivery. The use of the PRECEDE framework has provided a tool for systematically collating, interrogating and integrating the needs assessment data. This process has assisted in identifying a priority target group and care setting for service reform. The data, derived as part of the needs assessment method outlined in this chapter, have provided important baseline information to inform the R-PAC Project and to drive practice improvement.

Prior to proceeding to an action phase, the need assessment findings needed to be shared and considered by local aged care providers. Extensive consultation was required because, for this need assessment to be truly effective and action orientated, there needed to be a real commitment and acknowledgment by aged care providers that the promotion of a palliative approach was required within their facilities. These aged care providers also need to be prepared to embark on the changes required to systematically embed a palliative approach within their individual facilities. The consultation process adopted to further explore these issues and the methodology of the R-PAC Project will be discussed in detail in Chapter Three.
2.12 Reference list


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86. Mid North Coast Area Health Service. (2001). *Priority Health Program, Chronic Disease Management Model-Cancer*: Mid North Coast Area Health Service.


Chapter 3.

Mapping a Process for Action: Methodological and Conceptual Approach of the R-PAC Project
‘If you have come to help me, you’re wasting your time. But if you’ve come because your liberation is bound with mine, then let us work’

Lilla Watson

3.1 Introduction

The R-PAC Project design and methodological considerations have been underpinned by the philosophical premises of action research. Action research was chosen because it offered leverage to partner with key stakeholders in the clinical environment and engaged them in collaborative problem solving, research and the development of theory\(^1\). Another appealing aspect of utilising action research was its potential to embrace the social processes of managing and implementing practice change\(^2-5\). In spite of the theoretical differences of the quantitative and qualitative paradigms, mixed method data collection and analysis were adopted\(^6\). Mixed methods facilitated a rich and lucrative information source, and provided multifaceted perspectives that increased the depth and scope of the R-PAC Project’s data. This chapter will address the R-PAC Project’s aims, design considerations and methods employed. In addition the philosophical underpinnings of action research, as well as its strengths and limitations will be discussed.

3.2 Study Aim

The R-PAC Project aimed to collaboratively develop, implement and evaluate a sustainable model of care to facilitate the delivery of a palliative approach for older people admitted to residential aged care facilities in Coffs Harbour LGA.

3.3 Study design

The R-PAC Project is an action research study that employed mixed methods within a sequential transformative paradigm\(^7\). Briefly, action research was selected as the framework for the R-PAC Project because of its two basic aims of improvement and involvement\(^2\). Mixed methods allowed for the use of quantitative (structured data collection and statistical analysis) and qualitative (unstructured data collection and analysis) components within the same study\(^8,9\). A sequential transformative paradigm was chosen because it deliberately seeks under represented populations, such as aged care providers and older people in residential aged care facilities, and gives primacy to value-based and action orientated dimensions and uses mixed methods to promote change from the personal to the political
level\(^{(7)}\). This research design allowed an examination of the delivery of a palliative approach from a multifaceted perspective. In the conduct and design of the R-PAC Project qualitative and quantitative data were considered to be of equal significance and importance. Data collection and analysis of the R-PAC Project followed the action research sequence of reflection, assessment, planning, action and observation as illustrated in Figure 3-1.

**Figure 3-1**: Applying action research to the R-PAC Project

A summary of the sequence of the R-PAC Project’s five action research phases and the mixed methods undertaken in a sequential transformative design\(^{(7)}\) is provided in Figure 3-2.
As the R-PAC Project progressed the opportunity to employ a non equivalent group pre-test – post-test design to compare data becomes more evident. A non-equivalent group design is a common tool used in social research to compare the impact of an intervention. This design is structured in a pre-test–post-test manner using intact groups\textsuperscript{(11)}. There are several limitations to this approach primarily related to the absence of a control group which limits the ability to confidently attribute changes to an intervention\textsuperscript{(11)}. Maturation threatens internal validity because research participants over time age and potentially become more experienced and
skilful\(^{(11)}\). In spite of these limitations, this design is applicable to action research as the philosophical premises are not underpinned by a positivist framework of testing. Rather, action research adopts processes to foster a collaborative approach to negotiate goals using a range of enabling strategies\(^{(12)}\). For this reason a non-equivalent group design has been used extensively in quality improvement projects\(^{(13)}\) and the Collaborative Methodology\(^{(14, 15)}\), which utilises PDSA (Plan-Do-Study-Act) cycles to improve clinical care\(^{(16)}\). A non-equivalent group design allows for measuring the impact of interventions and driving ongoing clinical improvement.

### 3.4 Study setting

The R-PAC Project was based in the Coffs Harbour LGA. All residential aged care facilities \((n=9)\) operating in this LGA agreed to participate in the R-PAC Project. At the commencement of the R-PAC Project in early 2004, eight of these age care facilities were not for profit organisations and none had any designated palliative care beds\(^{(17)}\). Collectively, at this time these nine aged care facilities employed 78 registered nurses, 36 enrolled nurses and 284 care assistants\(^{(18, 19)}\). These aged care providers cared for 276 people classified as requiring high level care and 322 people classified as requiring low level care. In Australia, determining the level of care a resident requires is based on a regular assessment and application of the Residential Classification Scale\(^{(19, 20)}\).

### 3.5 Study participants

As part of the preliminary investigations, extensive consultation was undertaken with local health care providers from the acute health care, community and residential aged care sector, as outlined in Chapter Two. An emerging theme from the focussed palliative care needs assessment data was that older people in residential aged care facilities had unmet palliative care needs. In order to further explore these perceptions, five cohorts of research participants were identified as being potentially eligible for inclusion in the R-PAC Project. This included all consenting:

1. Nurses (registered or enrolled nurses) and care assistants (unregulated workers) employed permanently in any one of the nine residential aged care facilities in Coffs Harbour LGA.
CHAPTER THREE

METHODS

2. Local General Practitioners providing medical services to any of the nine residential aged care facilities in Coffs Harbour LGA.

3. Palliative care and aged care assessment team members employed by the local Area Health Service who provide a consultative service to the nine residential aged care facilities in Coffs Harbour LGA.

4. Older people living permanently in any of the nine residential aged care facilities in Coffs Harbour LGA, with the cognitive ability to consent to be involved in the R-PAC Project.

5. The ‘person responsible’\(^{(21)}\) for an older person living permanently in any of the nine local residential aged care facilities in Coffs Harbour LGA, with the cognitive ability to consent.

3.6 **The foundations of action research**

The origins of action research are generally attributed to the social psychologist Kurt Lewin, who during the 1940s was concerned with inter-group relations and minority problems\(^{(2, 5, 22)}\). He was interested in how people could enable themselves to improve their social situation through self education\(^{(1)}\). Lewin is thought to have been influenced by his colleague Jacob Moreno who sought to integrate theory and practice by perceiving researchers as social investigators\(^{(1)}\). Since then numerous writers from various disciplines including social science, education, psychology, and nursing have contributed to the evolution of action research which helps explain the variations in approaches\(^{(1, 23, 24)}\).

The influence of the philosopher Jürgen Habermas\(^{(25)}\) and the Brazilian educationalist Paulo Freire\(^{(26, 27)}\) is evident in the action research movement, which draws heavily on critical social theory and critical social science\(^{(28)}\). This philosophical framework is based on a desire to emancipate people from the constraints of an irrational and unjust life imposed upon them by hierarchical structures and social dominance\(^{(4, 23)}\). It is considered that empowering process can lead people to experience a transformative consciousness which is the catalyst for action\(^{(28)}\). Which makes decentralising and democratising the research process a key element of critical social theory\(^{(29)}\).

Much of Freire’s work focussed upon using these transformative experiences to empower the oppressed through a variety of self-directed, appropriate educational methods\(^{(27)}\). He
proposed that change occurred either through cultural invasion or cultural synthesis\(^{(27)}\). Cultural invasion is all about domination and occurs when an outsider imposes change in accordance with their own vision which acts to silence the group\(^{(27)}\). With cultural synthesis, the outsider comes to learn from and with the group and there are no imposed priorities\(^{(27)}\). The groups maintain their differences but integrate to collaboratively act on the reality to be transformed\(^{(27)}\). This theory is relevant to action research as it suggests that those who are invaded, rarely go beyond or expand on their views, ideas or practices imposed because there is no internalising or personal growth\(^{(26)}\). This theory provides valuable insights into how researchers and participants can work collaboratively to develop priorities and guidelines for action\(^{(10, 26)}\). Adopting a collaborative partnership approach ensures that people are not research or education objects but rather active participants, who are able to name the problems and solutions and in the process change their oppressive circumstances\(^{(30)}\). This idea of an empowering ‘bottom up’ approach to change is a central tenet of action research\(^{(1)}\).

Therefore, action research is a post positivist research method and as such is concerned about empowerment\(^{(31)}\). This is in contrast to the positivist framework which seeks to control and contain a phenomenon. The action research process seeks to empower individuals and organisations to challenge traditional boundaries in respect of methods and significantly power relationships\(^{(2, 3)}\). It is focussed on issues surrounding the conduct of empirical research in an unjust world and is driven by an imperative to empower those involved and contribute to the generation of change enhancing social theory\(^{(32)}\). Action research is fuelled by a desire to disrupt the dominant power relations in an effort to recreate new and just social situations in a process described as ‘…a project of possibility’\(^{(31)}\)(p.174).

### 3.7 Defining action research

Despite action research having existed for over 50 years and being used by a variety of disciplines, it remains difficult to define and is fraught with methodological challenges\(^{(22, 33)}\). Most definitions have evolved considerably since Lewin’s original work, with action research now being considered an approach to research as opposed to a specific method\(^{(33, 34)}\). The majority of definitions incorporate several defining characteristics: collaboration and participation; democratic processes; and the ability to simultaneous contribute to social change and social science\(^{(5, 23)}\).
Hart and Bond\(^{(2)}\) have expanded upon this work to develop an action research typology which has seven distinguishing characteristics: i) an educative base; ii) a focus on individuals as members of social groups; iii) utilises methodologies that are problem focused, context specific and future orientated; iv) inclusion of a change intervention; v) an aim to improve and involve; vi) uses cyclic processes; and vii) is founded on a research relationship and degree of collaboration\(^{(2)}\). Within this typology there are four action research approaches that are conducted in accordance with the researcher’s philosophical positions which tend to fall somewhere between a consensus and conflict model of society\(^{(2)}\) (Figure 3-3).

**Figure 3-3: Overview Hart and Bonds Action Research Typology**

An ‘experimental approach’ is said to occur when the action research is focused on conducting an intervention to provide a controlled outcome with causal processes that can be generalised\(^{(2,10)}\). An ‘organisational approach’ adopts a top-down approach with the most powerful group defining the problem for others and then setting about to achieve tangible outcomes\(^{(2,10)}\). Within the context of a ‘professionalizing approach’ the problems identified by the group become the focus of attention, with the group being lead through dynamic and reflective processes aimed at improving practice\(^{(2,10)}\). An ‘empowering approach’ involves a conscious raising ‘bottom-up’ approach to identify and address problems as group awareness increases\(^{(2,10)}\). The diversity of stakeholders involved in an empowering approach allows for
multiple outcomes\textsuperscript{(2, 10)}. Given action researches’ dynamic nature and its tendency to evolve over time there is often some overlap of approaches\textsuperscript{(2)}. Despite this typology being a helpful construct, a recent systematic review of health related action research found that most studies didn’t fall neatly into these four approaches and that a more workable definition was indicated\textsuperscript{(1)}. The definition developed by Waterman and colleagues following an extensive review of the literature and robust debate has been adopted:

\textit{Action research is a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem-focused, content specific and future-oriented. Action research is a group activity with an explicit critical value basis and is founded on a partnership between action researchers and participants, all of whom are involved in the change process. The participatory process is educative and empowering, involving a dynamic approach in which problem identification, planning, action and evaluation are linked. Knowledge may be advanced through reflection and research, and qualitative and quantitative research methods may be employed to collect data. Different types of knowledge, including practical and prepositional may be produced by action research. Theory may be generated and refined, and its general application explored through the cycles of action research process\textsuperscript{(1)} (p.11).}

This comprehensive definition describes action research’s defining attributes and acknowledges that its associated goals are essentially about education, empowerment, change and theory generation\textsuperscript{(1, 34)}. It concedes that the whole purpose of action research is to simultaneously gain an understanding of the social system in order to address the problem(s), identify the best opportunity for change whilst generating new knowledge about the system\textsuperscript{(2, 35)}. Collaborative action is a critical element of this process and helps to bring about change in a given situation\textsuperscript{(36)}; it requires the researcher to work democratically with and for participants, rather than undertaking research on them\textsuperscript{(22, 37)}. Employing these democratic processes also ensures that the research process and outcomes are more meaningful to participants and encourages them to examine and reflect on usual practice, which is critical.
for change\(^\text{(22)}\). In addition, these democratic processes enable the action research cycles to be responsive to events as they naturally occur in the field\(^\text{(22)}\).

### 3.8 Key processes of action research

As previously described and illustrated in Figure 3-1, action research involves cycles of reflection, planning, acting and evaluating\(^\text{(10)}\). The action research process hinges on reflecting on the current situation in order to gain an experiential understanding of the problematic situation and the generating of research question(s)\(^\text{(4)}\). Identifying and investigating the problem and exploring the literature is a key step from which change or improvement strategies may be generated\(^\text{(4, 36)}\). These strategies are then put into action, the impact of actions observed, monitored and critically evaluated\(^\text{(4)}\). It is often during the action research process that a creative period of transformation occurs where a new world of possibilities becomes apparent to participants, enabling them to test new and improved actions\(^\text{(4, 38)}\). The action researches cyclic processes are repeated until participants reach a consensus that the problem is resolved or practical considerations, such as time or resources, terminate the study\(^\text{(36)}\).

### 3.9 Strengths of action research

Contemporary health care systems promoting evidence based practice and clinical governance strive to engage health care providers in practice driven research to strengthen the nexus between research and usual practice\(^\text{(16, 22, 39)}\). Action research is one research approach that can be readily adopted by health care providers concerned with improving the quality of care and service delivery\(^\text{(40)}\). Part of the appeal of action research lies in its ability to bridge the gap between theory, research, practice and scientific methods\(^\text{(5, 36)}\). In addition, this research approach can positively influence practice while generating data that can be shared with a wider audience and produce tangible benefits\(^\text{(22, 34)}\). However, the epistemological basis of action research differs significantly from that of the traditional sciences in that it aims to produce context specific and situational knowledge\(^\text{(41)}\); it therefore lends itself to studying issues in their natural environment\(^\text{(42)}\). This flexibility has enabled action research to be used in a variety of health and education settings to effect change\(^\text{(1-3, 36)}\). Action research assists in understanding and addressing complex problems or facilitating the development of relevant and appropriate practices, services and organisational structures\(^\text{(1)}\). The cyclic process of action research makes it most appropriate to the needs of organisations wishing to drive...
change within their operating environment\(^{(2)}\). Action research is also effective in fostering better practices across inter professional boundaries and across the care continuum\(^{(1)}\).

Action research uses various methodological process, some of which may be identified prospectively while others are developed with participants as the study progresses through the action research process\(^{(5)}\). In action research “…the researcher is constantly challenged by events and by ideas, information and arguments posed by the project participants”\(^{(43)}\)(p.42). This is particularly true of clinical areas where things can change rapidly and frequently. Conducting action research in this dynamic environment requires the researcher to adopt a flexible stance and ability to cope with these constant changes. Despite these challenges, adhering to action researches responsive and creative process ensures that both the researcher and the participants are fully engaged in reflection and learning for the duration of the study\(^{(44)}\).

The cyclic processes of defining the problem, initiating and evaluating change requires sustained collaboration between researcher and participants, promoting close working relationships and a deeper understanding of the issues\(^{(42)}\). Reflective practice is an integral component of the action research process focusing on participant’s own meanings and interpretations of the process and its impact and outcomes\(^{(34)}\). Promoting reflective practice is an important element of all action research as it can act as a medium to increase participants’ level of control over change, the action they need to take and ultimately the potential to influence clinical practice\(^{(36)}\). Importantly, active engagement of participants in the change process increases the potential for sustaining these changes made through the research journey\(^{(4, 45, 46)}\). However, success in action research ought not to be judged solely on the size of changes made and implementation of solutions, but also from the shared learning and knowledge transfer that occurs during the action research process\(^{(22)}\). As it is often during these cyclic process that novel and unexpected solutions to specific problems emerge and these too are important markers of success\(^{(22)}\).

**3.10 Challenges associated with action research**

Unlike other forms of research, action research doesn’t always progress in a linear fashion rather it follows a somewhat unpredictable research process that is not always continuous\(^{(2, 47)}\). An implicit requirement of the action research process is that the researcher facilitates the research process rather than directs it. This requires a preparedness from the researcher that
their relationship with participants will be dynamic and likely to undergoing continuous evolution\textsuperscript{(47)}. Significantly, it relies on the researcher tolerating ambiguity and uncertainty and accepting that the action research journey and its final destination are somewhat unknown. In research the can be quite challenging as it can create political dissonance and ethical ambiguity\textsuperscript{(40)}. However, the action research process can be a transforming experience, as participants are provided with an opportunity to look at the organisation and their positions from different perspectives and identify action for change\textsuperscript{(4)}. However, if the organisation is not committed to the change process it can lead to plenty of reflection with little evidence of change, which can be frustrating and disheartening for participants\textsuperscript{(40)}. Similar to the prerequisites for an effective needs assessment, it is necessary to ensure that there is organisational desire to explore innovation and change prior to embarking on the action research process\textsuperscript{(41)}.

Action research is an approach that is primarily concerned with participation which makes active engagement and support of participants a necessary prerequisite for it to proceed and non participation one of its greatest threats\textsuperscript{1, 4}. As the action research process is driven by key stakeholders it is essential to recruit a group of participants who will be committed to the project goals and the journey it entails\textsuperscript{(4)}. Identifying and then actively engaging these interested stakeholders as members of a Critical Reference Group is vital for a collaborative partnership approach to reform\textsuperscript{(4, 48)}. Further, the establishment of this key stakeholder group assists with sustainability, as at the end of the study these participants will have developed new insights, a shared purpose and have the potential to continue on with the collaborative processes\textsuperscript{(4)}.

Action research requires that the researcher establishes an ongoing and purposeful relationship based on democratic principles with the participants\textsuperscript{(22)}. But this relationship presents several ethical and political challenges depending upon where the researcher is situated within the organisation, either as an internal or external researcher\textsuperscript{(40)}. Although the internal researcher has greater access to participants and the sphere of action, this proximity can often be problematic and difficult to manage due to role duality\textsuperscript{(40, 49)}. Action research introduces a greater level of exposure for participants, the organisations involved and the researcher because it requires some judgement to be made about individual and/or organisational norms, beliefs and practices, all of which is intensely political\textsuperscript{(49)}. It challenges the status quo which can be extremely threatening to individuals, cultures and systems\textsuperscript{(40)}. In turn, this may cause conflict between participants work and research activities\textsuperscript{(40)}. If the need
to alter practice(s), policies and procedures is identified through the action research process it raises power issues around whether the participants have the necessary authority and organisational support to drive these changes\(^{(40)}\). All of which places the researcher and participants professional reputation within the organisation at risk\(^{(40)}\). Being an external researcher is also fraught with complexities, primarily ensuring that the research process is truly collaborative and that authority is not vested with the researcher. A collaborative approach is critical to ensuring that the changes are not resisted, are fully owned by the participants and don’t cease at the completion of the action research process\(^{(40)}\).

Like all other forms of research, action research is bound by the ethical need for honesty, integrity, not doing harm, obtaining informed consent, maintaining confidentiality, upholding the right to withdraw and maintaining data integrity\(^{(50)}\). There are unique challenges in action research complying with these ethical considerations. The close relationship between researcher and participants, which is critical to action research has ethical implications for informed consent and anonymity\(^{(40)}\). Meyer\(^{(51)}\) suggests that traditional forms of consent are often inadequate in action research as co-operation is often to some degree forced and that it is also unrealistic for the researcher to withdraw when confronted with small pockets of resistance. Yet obtaining informed consent is essential, as the changes that occur as part of the action research process can sometimes cause anxiety and fear\(^{(40)}\). It is also difficult to get informed consent for an intervention that is yet to be fully determined. Action research also challenges the researcher to achieve the delicate balance of maintaining confidentiality while ensuring openness with the data\(^{(40)}\), which requires careful consideration and negotiation prior to commencing the research process.

Achieving scientific rigor is another challenge of the action research process and it has faced a variety of criticisms with it’s proponents being required to defend validity claims\(^{(24)}\). Rolfe\(^{(52)}\) suggests that all research is essentially conducted along a quantitative-qualitative continuum and, therefore, a continuum of quality criteria are required to determine the validity, trustworthiness and rigor of all research. The notions of power, participation and ethics have been central to this debate\(^{(24)}\). As participation is a distinguishing feature of action research\(^{(1)}\) the regular feedback to participants is an important contribution to the scientific rigor of the study. Issues of validity, reliability and reflexivity are important methodological considerations when undertaking action research\(^{(53)}\). The quality of the research is said to be revealed in the writing up\(^{(52)}\). This requires the researcher to adequately describe the research and provide explicit details of the findings, ensuring that a knowledgeable outsider has
sufficient information to judge the relevance of the research and the degree to which the findings are transferable to their practice setting\(^{(33)}\). Quality can be enhanced by an audit trail providing sufficient information detailing the rationale underpinning the research, the decision made during the process and a reflexive research journal\(^{(52)}\).

The involvement of the researchers in the process of change and collaboration prevents the researcher from being neutral and value free\(^{(34)}\). The action research process is also influenced by the personal qualities and skills of the researcher, particularly their ability to: deal with group dynamics; pragmatic issues that arise during the course of the research; obtaining consensus and maintaining the group’s momentum. Given these key requirements, the researcher’s inter-personal attributes are crucial to the success of the action research process\(^{(47, 54)}\). To ensure the adoption of new behaviours and the ongoing success of the action research process the researcher needs to delicately balance the role of acting as a catalyst whilst simultaneously fostering a sense of ‘ownership’ amongst the participants\(^{(36)}\).

Action research is essentially action that is researched, changed then re-researched which makes it a time consuming process\(^{(1)}\), especially as it involves talking, thinking, sharing the data and reflecting with participants\(^{(4)}\). Importantly, the time consuming nature of action research must be factored into the research design\(^{(1)}\). Conducting this type of research in a dynamic clinical environment is also challenging because the clinical demands often take precedence over the research. Further, workforce issues related to staff stability and turnover can be difficult in a study that is conducted over an extended period of time. This is particularly relevant in the aged care workforce, which is known to have a high turnover and therefore a less stable workforce\(^{(55, 56)}\).

All of these potential barriers and challenges need to be considered and addressed prior to commencing an action research study in order to minimise their impact on the research process\(^{(1)}\).

### 3.10.1 Specific strategies employed in the R-PAC Project to address these challenges

Given the R-PAC Project’s population focus it was anticipated that a collaborative research partnership would be formed between the researcher and participants within the nine residential aged care facilities. As an external researcher, with no legitimate authority within the nine local residential aged care facilities to drive the change process a governance process
was adopted to help promote participation, collaboration and co-operation. Consequently, the researcher’s role in the R-PAC Project was to act as a facilitator and enabler. In this role the researcher was able to assist with the diagnostic process, provide ongoing support and feedback to participants, whilst facilitating and enabling the action research process across organisations but with no operational responsibility for carrying out the changes required within the individual facilities\(^{(57)}\).

**Figure 3-4: Interaction of the R-PAC Project’s three key stakeholder groups**

As part of the diagnostic phase of the R-PAC Project’s action research process, extensive expert consultation, interviews, and focus groups were undertaken with aged care providers to determine their knowledge in respect of delivering a palliative approach to care within their individual residential aged care facilities. Overwhelmingly key stakeholders, including nurses, administrators, general practitioners and family members, recognised the importance of this philosophical approach and acknowledged barriers as well as facilitators to this process. Importantly, all nine directors of nursing enthusiastically supported the opportunity to partner with the researcher to collaboratively identify an intervention that aimed to promote the delivery of a palliative approach to care for residents. This support facilitated the establishment of the Critical Reference Group, whose real world insights were essential to collaboratively developing strategies to address the unmet palliative care needs of older people in local aged care facilities\(^{(48)}\). This group was one of three key stakeholder groups.
that guided and supported the development of the R-PAC Project: i) Mid North Coast Rural Palliative Care Project Advisory Group; ii) Aged Care Professionals Group; and iii) Critical Reference Group (Figure 3-4) (Appendix 2).

The governance process established for the R-PAC Project ensured that the overall direction that the action research process took was guided by the Critical Reference Group. This stakeholder group was composed of interested participants from across the nine residential aged care facilities. These participants all had a shared desire to enhance palliative care delivery within their facility. They also agreed to become research partners and engage in a process whereby they would reflect on their experiences and collaboratively identify workable solutions and strategies to address this issue\(^{(48)}\).

The other two stakeholder groups also played important roles in supporting and guiding the R-PAC Project. The Rural Palliative Care Project Advisory Group, which included key stakeholders involved in the delivery of palliative care across the care continuum in Coffs Harbour LGA, was responsible for strategic direction and governance. This Project Advisory Group provided support to the Critical Reference Group and approved R-PAC Project expenditure. In addition, the researcher met bi-monthly with the established Aged Care Professionals’ Group, which consisted of the senior nurses responsible for the management of the nine residential aged care facilities and the Aged Care Assessment Team. These meetings provided the researcher with an opportunity to update the nurse managers on the R-PAC Project and seek their advice, comments and concerns about the project’s direction. In addition, it provided the nurse managers with an opportunity to share and get support and advice about the implementation of a palliative approach within their facility.

The way in which these three groups were configured ensured that all key stakeholders were provided with ample opportunities to be involved and have input into shaping the R-PAC Project. This governance structure helped to mitigate many of action research’s inherent risks by adopting processes that were inclusive, consultative and promoted co-operation and collaboration.

### 3.11 Developing and evaluating the R-PAC Project using mixed methods

Action research is a conceptual framework as opposed to a specific method\(^{(22)}\) and draws on a variety of data collection methods. This makes mixed methods most appropriate to action research, with the data collected being used to shape and propel the action research process.
Mixed methods are also indicated for projects, survey, evaluation and field research that use multiple sources of information\(^6\). The term mixed methods has been used to describe research that uses “…qualitative and quantitative data collection techniques in either parallel or sequential phases”\(^8\)(p.11) and it is “the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study”\(^58\)(p.17).

Mixed methods are particularly useful as they allow multifaceted observations and adaptation of a range of research methodologies to a research setting and questions with unique characteristics\(^6\). Mixed methods are achieved by using qualitative and quantitative research methods in both exploratory and evaluative contexts and allowing a range of theoretical perspectives, all of which are reconcilable with action research’s focus on involvement, empowerment and future orientation\(^3\).

### 3.11.1 Theoretical perspective

As previously described, the R-PAC Project design was governed by an overarching action research framework and employed mixed methods for data collection within a sequential transformative paradigm\(^6\). This paradigm deliberately seeks under represented populations, gives primacy to value-based and action orientated dimensions and uses mixed methods to promote change from the personal to the political level\(^7\). In this paradigm, one type of data provides a basis for the collection of another type of data. As the focus is on traditionally under served groups, sharing the data with participants is an important strategy that enables the group to determine the lessons learnt and identify options for action\(^7\). All of these principles are congruent with those of action research which involve: active engagement of participants, the establishment of a critical reference group to guide the research process, and utilising the data to drive the action research process through the various cycles of reflecting, planning, acting and evaluating\(^10\).

The R-PAC Project’s action research processes hinged on reflecting on the current situation in order to gain an experiential understanding of the problematic situation and assisted with the generation of the research questions\(^59\). The specific research questions that the researcher and the critical reference group sought to answer during the R-PAC Project are detailed in Table 3-1. The expansive scope of these research questions suggested that neither purely qualitative nor quantitative methods of data collection would be adequate to provide
comprehensive insight into this complex care issue\(^7\). Using mixed methods would allow the researcher to draw from the strengths and minimise the weaknesses of the quantitative and qualitative paradigms across the R-PAC Project’s eight sub studies\(^{59}\). It was considered that mixed methods would facilitate a comprehensive understanding of the phenomena (palliative care delivery) and the context in which it was occurring (residential aged care)\(^7\).

It was also anticipated that conducting a mixed methods research design within an action research framework would help to hasten the understanding of the area of inquiry and achieve the R-PAC Project’s research goals in a timely manner\(^3\). This occurred because mixed methods offered a practical and outcome-orientated method of inquiry and complimented the action research cycle of reflection, assessment, planning, action and observation.
### Table 3-1: R-PAC Project’s research questions and data collection methods

<table>
<thead>
<tr>
<th>Research questions</th>
<th>Research method</th>
<th>Study</th>
<th>Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) What are the population based palliative care needs of older people living in residential aged care in Coffs Harbour, New South Wales?</td>
<td>Focused palliative care needs assessment</td>
<td>Study A</td>
<td>Preliminary investigations</td>
</tr>
<tr>
<td></td>
<td>Time 1: Chart audit – End-of-life care</td>
<td>Study B</td>
<td>Phase 1</td>
</tr>
<tr>
<td>(2) What are the key factors in facilitating palliative care delivery in residential aged care in Coffs Harbour, New South Wales?</td>
<td>Time 1: Focus groups: aged care managers, nurses and care assistants</td>
<td>Study C</td>
<td>Phase 1</td>
</tr>
<tr>
<td>(3) What are the major barriers to palliative care delivery in residential aged care in Coffs Harbour, New South Wales?</td>
<td>Time 1: Focus groups: aged care managers, nurses and care assistants</td>
<td>Study C</td>
<td>Phase 1</td>
</tr>
<tr>
<td></td>
<td>Time 2: Survey aged care managers, nurses and care assistants</td>
<td>Study D</td>
<td>Phase 1</td>
</tr>
<tr>
<td>(4) What are the palliative care knowledge, skills, attitudes and beliefs of clinicians working in residential aged care in Coffs Harbour, New South Wales?</td>
<td>Time 1: Focus groups GPs</td>
<td>Study E</td>
<td>Phase 3</td>
</tr>
<tr>
<td>(5) What are the information needs, resources and systems required for the successful delivery of a palliative approach to end-of-life care in residential aged care facilities in Coffs Harbour, New South Wales?</td>
<td>Time 2: Focus groups: aged care managers, nurses and care assistants</td>
<td>Study F</td>
<td>Phases 3</td>
</tr>
<tr>
<td></td>
<td>Time 2: Survey aged care managers, nurses and care assistants</td>
<td>Study G</td>
<td>Phase 4</td>
</tr>
<tr>
<td></td>
<td>Time 2: Chart audit – End-of-Life Care</td>
<td>Study H</td>
<td>Phase 4</td>
</tr>
<tr>
<td>(6) What are the key components of a sustainable model of care to facilitate the delivery of a palliative approach to the end-of-life care for older people in residential aged care in Coffs Harbour, New South Wales?</td>
<td>Model of care development</td>
<td></td>
<td>Phase 5</td>
</tr>
</tbody>
</table>

The decision to utilise mixed methods in the R-PAC Project triggered a cascade of other methodological considerations related to: implementation sequence, priority and integration.
3.11.2 Implementation sequence

The R-PAC Project utilised a range of methodological process and data collection methods, some of which were identified prospectively while others were developed with the participants as the action research process unfolded\(^6\). This resulted in data collection occurring both sequentially (between phases) and concurrently (within phases) within a transformative process (Figure 3-5). The R-PAC Project’s sequential data collection occurred between phases, with the data from the previous phase being used to propel the action research process and inform subsequent data collection. Concurrent data collection occurred predominately within the phases, which facilitated a large amount of data to be collected in a relatively short period of time\(^60\).

3.11.3 Priority

In the R-PAC Project, equal emphasis was afforded to both qualitative and quantitative methods to ensure that the R-PAC Project generated data that was in some stages exploratory, while in others focussed on process and summative evaluation to drive the process forward \(^59\). In adopting this approach it was appreciated that the knowledge gained from each data set had the potential of being either complementary, incommensurate or contradictory\(^61\). In the context of action research, the emerging of contradictory results is indicative of the need for further exploration and consultation. Thus, the cyclic nature of the action research process helped to ensure that what was learnt from each data set, regardless of whether it was complementary or contradictory always guided the subsequent phase of the project. Further, the use of a mixed method approach was advantageous in reconciling and validating a range of data sets in sequential and concurrent phases. This engagement ensured that as new knowledge emerged it was acknowledged and addressed. This information facilitated the research design to evolve in response to the conditions encountered and the information gathered during each phase\(^59\).
Mixed methods research is more than just collecting qualitative and quantitative data in the same way that action research is more than an ad hoc collection of disparate processes. Rather, the use of mixed methods demands that the data be mixed or integrated, compared, contrasted, appraised and synthesised at some point\(^6\). The ability to extract adequate information from the data is one of the major rationales for mixed methods data analysis. As previously described, the majority of the R-PAC Project’s data were collected and analysed separately in a concurrent (within phase) and sequential (between phases) design, with all data
from each phase being used to inform the subsequent phase of the action research process (Figure 3-5). The opportunity to integrate different types of data as part of the action research iterative processes was critical to maximising the R-PAC Project’s potential whilst also determining its effectiveness.

### 3.11.5 Challenges for the novice researcher

Mastering mixed methods research is not without its challenges and limitations. Utilising mixed methods within action research adds to the complexity of the research process. This is amplified by the inherent challenges associated with conducting and reporting action research’s dynamic processes\(^{(43)}\). A significant amount of data was collected during each phase of the R-PAC Project’s action research phases which required a management system to deal with qualitative, quantitative and integrated data. The utilisation of mixed methods also required the researcher to have a sound understanding of the defining characteristics, strengths and weaknesses of both quantitative and qualitative paradigms. Developing these competencies takes considerable time; effort and experience, all of which makes a collaborative research approach a pre-requisite for utilising mixed methods. Unfortunately, this resource requirement is often a major barrier to employing mixed methods. Prior to embarking on a mixed methods study the researcher needs to consider and address these limitations to maximise the potential to mix or combine data collection strategies, which is the fundamental principle of mixed methods research.

### 3.11.6 Summary of R-PAC Project’s mixed methods

As previously discussed, neither the qualitative or quantitative data sets were privileged so each set was considered to be of equal weight. In addition, the data collection methods were complimentary and helped extend the depth and scope of the change process. Further, a mixed methods design has allowed for corroboration of the data, with the same results being derived from both qualitative and quantitative data sets\(^{(62)}\). On occasions it has allowed for elaboration, with the qualitative data analysis exemplifying how the quantitative findings apply in particular cases\(^{(62)}\). There was also scope for complementary data, where the qualitative and quantitative findings varied but together they generated new insights\(^{(62)}\). In addition a mixed methods design also allows for the identifying of contradictions, occurring when the findings from the qualitative and quantitative data conflict with one another\(^{(62)}\).
All results obtained from the data were communicated to the participants and it was through the reporting and sharing of results that changes in social process and relationships began to emerge\(^{(63)}\). Each of the R-PAC Project’s data sets has helped inform the collection of a new set of data and the next stage of the action research process. This iterative process ensured ‘voices from the field’ were accurately documented\(^{(64)}\) and facilitated a collaborative process that enabled the participants to act on the research findings. These approaches are congruent with an action research process. Being able to align the mixed methods design with the action research process was an important consideration for the R-PAC Project. Utilising a mixed methods design in the R-PAC Project has assisted in corroborating the data and expanding the researcher’s and participants’ understanding of the phenomena of delivering a palliative approach in residential aged care facilities\(^{(59)}\).

### 3.12 Position of researcher in the action research process

The choice of the action research as the process driving the R-PAC Project was congruent with my personal commitment to principles of social justice and equity. Having previously worked with marginalised community members both as a community based palliative care nurse and sexual health educator I was cognisant of how issues of power, politics, gender, role and status impact on people’s lives. I was also mindful at the outset of the R-PAC Project of these issues, especially given aged care provider’s marginalised position within the health care sector in terms of wages, professional status and isolation\(^{(65, 66)}\). It seemed that adopting the role of facilitator and enabler would place me in the best position to provide aged care personnel with a supportive and empowering environment in which they could collaboratively work to address their identified needs. Action research allowed for dynamic, iterative, inclusive and reflective processes to be utilised with the aim of improving the care of residents as well as addressing a range of nurses’ and care assistants’ personal and professional issues. The action research process also helped ensure that due attention was paid to the subjective meanings for participants and the factors that facilitating a sense of joint ownership of the R-PAC Project’s process and outcomes\(^{(67)}\). Enabling aged care management, nurses and care assistants to assume ownership of the R-PAC Projects initiatives was viewed as being critical to its long term sustainability.

Having been a Palliative Care Clinical Nurses Consultant in Coffs Harbour and known to some providers within the residential care sector, it was inevitable that many aged care nurses and care assistants would perceive me as a palliative care expert. Despite my significant
palliative care expertise, I had limited gerontological knowledge and experience, having never worked in the aged care setting, nor having any close personal association with anyone residing in aged care. Therefore it was important that I share with participants that I too was a learner, both as a neophyte researcher and as a newcomer to gerontology. The R-PAC Project participants subsequently took on the role of ‘teachers’ as they shared their extensive aged care expertise and introduced me to the speciality of aged care. So in many respects, the R-PAC Project has been on a shared journey of discovery for all.

3.13 Complexity of reporting action research

Adhering to the dynamic principles of action research adds to the complexity of the research process and amplifies the challenges associated with reporting action research and mixed methods studies\(^{(1, 68)}\). In order to increase clarity for the reader, issues related to quantitative and qualitative data are discussed individually.

3.13.1 Preliminary Investigations: A focussed needs assessment

As described in Chapter One, the funding of the Mid North Coast Rural Palliative Care Project provided the impetus to identify potential target populations that may have unmet palliative care needs within the local community. This initiative provided an opportunity to undertake a range of preliminary investigations, including a focused palliative care needs assessment as discussed in Chapter Two. At the conclusion of the preliminary investigations there was sufficient evidence of need to develop an initiative that focused on enhancing the delivery of a palliative approach to older people in residential aged care facilities. The R-PAC Project emerged from this identified need.

3.13.2 Identifying potential priorities for action and stakeholder engagement

A range of stakeholder consultation was undertaken as part of the preliminary investigations. It was evident that there was a network of health care providers who were concerned about enhancing the provision of palliative care to older people in local aged care facilities. These stakeholders were keen to be actively involved in exploring options to address this area of need and the research questions. This extensive consultation process helped to ground the research process in a substantive understanding of the relationship between the phenomena of interest and the social and temporal contexts in which they occurred\(^{(69)}\).
Importantly, these stakeholder consultations generated initial participatory momentum for the action research process, which was maintained throughout the R-PAC Project. The endorsement and support of key sponsors and stakeholders facilitated the establishment of a Critical Reference Group to guide the development and implementation of the R-PAC Project. Expressions of interest to participate in the R-PAC Project were sought from interested aged care nurses, enrolled nurses, and care assistants. The input of a wide cross section of key stakeholders to the R-PAC Project, through the Mid North Coast Rural Palliative Care Project Advisory Group, Critical Reference Group and Aged Care Professionals Group enhanced the relevance of the inquiry, the meaningfulness of the data and added to the creativity, relevance and effectiveness of the subsequent actions (4).

3.13.3 Methodological considerations: Mapping a process for action

As part of the preliminary investigations a full exploration of the methodological and conceptual approaches was also undertaken. In considering the various approaches the researcher wanted a method that would allow for an in-depth exploration of the palliative care needs of older people in residential aged care. But equally important was selecting a method and research design that would support aged care providers to respond to this demand and be active participants in the process. Once the issue of improving palliative care in residential aged care was identified, the R-PAC Project was driven by the aims of engaging, encouraging and empowering residential aged care nurses and care assistants to address their concerns. The action research process of exploration and ability to be responsive to contexts, rather than being prescriptive in its measures and processes, is an ideal framework in which to ground this research (70).

3.13.4 Phase One: Developing priorities for action

In order to progress the R-PAC Project, gaining a greater understanding of the level of palliative care currently being delivered to residents, the views and attitudes of aged care nurses and care assistants and their palliative care competencies was considered a priority. A chart audit (Study B) appraising residents’ end-of-life care, a series of focus groups (Study C) and a survey (Study D) were conducted during Phase One. The data obtained from these three separate studies is reported in Chapter Four. Following the collection and analysis of this data it became apparent that there was scope within the R-PAC Project design for the use
of a non-equivalent group design using pre-test and post-test study groups, consisting of two discrete populations, for the:

1. Chart audits - residents who had died in 2003 (Time 1) and 2005 (Time 2); and

2. Survey and focus groups - nurses and care assistants employed in local residential aged facilities in 2004 (Time 1) and in 2006 (Time 2).

As these are non-equivalent groups, the demographic characteristics of each of these groups (residents and aged care providers) at pre-test are presented in Chapter Four (Time 1) and post test, in Chapters Six and Seven (Time 2).

3.13.5 Phase Two: Developing and implementing a multifaceted intervention

The Critical Reference Group assembled for this project developed the multifaceted intervention that was shaped by the Phase One data and the release of ‘Guidelines for a palliative approach in residential aged care’ in April 2004\(^{(71)}\). These evidence based guidelines have since been endorsed by the National Health and Medical Research Council\(^{(72)}\) and provided considerable leverage on a policy and clinical level for the R-PAC Project. The multifaceted intervention aimed to increase the palliative care knowledge, skills and confidence amongst residential aged care nurses and care assistants, which is discussed in Chapter Five.

Along with the learning and development, organisational and change management strategies that were identified as being required to improve care, the R-PAC Project’s action research process provided the Critical Reference Group with a mechanism to monitor the project’s progress. It also allowed opportunities to identify facilitators and barriers to promoting the delivery of a palliative approach and promoted the exploration of emerging issues and outcomes. The active involvement, participation and collaboration of the Critical Reference Group in developing the multifaceted intervention and combined research processes contributed to participants’ empowerment. Empowerment has been described as a labour intensive, long term process of social transformation achieved through a continuous series of ‘small wins’\(^{(73, 74)}\). Throughout the R-PAC Project the Critical Reference Group and all participants involved in the multifaceted intervention were encouraged to reflect on their ‘small wins’ and use the lessons learnt to shape and guide future action, all of which are congruent with action research’s cyclic processes\(^{(73, 74)}\).
3.13.6 Phase Three: Reflecting on the action

After the multifaceted intervention, as described in Chapter Five, had been in operation for 12 months, it was time to pause and reflect on the journey to date. Another series of focus groups was undertaken with aged care nurses and care assistants (Study E) whilst a separate series of focus groups were undertaken with local General Practitioners (Study F). These studies are reported in Chapter Six.

3.13.7 Phase Four: Measuring the impact of the action

The survey (Study G) was re-administered to detect any changes in aged care nurses and care assistants palliative care competencies and confidence. A repeat chart audit (Study H) on end-of-life care was undertaken to measure the degree to which the multifaceted intervention had impacting on the delivery of palliative care to older people in the nine residential aged care facilities.

3.13.8 Phase Five: Navigating a course for further action

The final phase of the R-PAC Project involved the development of a sustainable model of care to facilitate the delivery of a palliative approach to care for older people in residential aged care facilities, which became more concrete and precise as a result of the action research process\(^5\). As part of this process, planning for a six month trial of multidisciplinary case conferencing in four residential aged care facilities was completed and conceptual work for the development of a palliative approach pamphlet for residents and their families undertaken. This process assisted in facilitating systems and processes to support the primary care interface, promoting of advance care planning and enabling continuity of care, which are discussed in Chapter Eight.

Operating in parallel, but with a dearth of information in the literature and little evidence to guide the process, was a conscious decision by the researcher to develop an exit strategy to facilitate disengagement from the action research process and, in turn, from the Critical Reference Group by December 2006. Every endeavour was made to ensure that the residential aged care nurses and care assistants had an opportunity to determine the fate of the group at the conclusion of the R-PAC Project and these issues are explored further in Chapter Eight. In addition exploring strategies to ensure the ongoing sustainability of the changes made was also required\(^{46}\).
3.14 Ethical considerations

Many of the ethical challenges associated with action research, as previously described, are context specific. In the absence of clear guidelines, identifying how these ethical issues were to be managed was discussed in detail with the Critical Reference Group prior to the commencement of the R-PAC Project. The three critical ethical questions proposed by Williamson and Prosser\(^{(40)}\) guided these conversations and assisted in establishing acceptable processes.

It was anticipated that the researcher and participants would be collaborating closely during the R-PAC Project and that this presented considerable challenges for guaranteeing confidentiality and anonymity. In addition to the usual ethical strategies employed in research to preserve participants’ confidentiality and anonymity, it was considered that extra protection was afforded to participants, through the R-PAC Project’s population focus, governance, adoption of collaborative processes and potential to engage large numbers of participants across nine residential aged care facilities. As action research often has political consequences it was considered that these strategies, particularly the governance process and participation rates would also help avoid doing harm to the participants\(^{(40)}\). In addition, the opportunities for critical and reflexive dialogue integral to the action research process would provide opportunities for participants to articulate their personal and professional moral concerns\(^{(40)}\). It was acknowledged that, as action research evolves over time, gaining informed consent needed to be a continuous process. It was also agreed that the researcher would use ongoing member checking, adopt a process of continuous negotiation with the participants and obtain written consent for participation in specific activities undertaken as part of the R-PAC Project’s data collection.

Approval for the study was obtained from the University of Western Sydney Human Research Ethics Committee (HREC) to conduct the R-PAC Project, approval number HREC 05/060 (Appendix 3). Information about the aim and methods of the study, and about consent, confidentiality and withdrawal, was given to participants orally and in a written information sheet prior to written consent being obtained (Appendix 4).

Permission was granted by the Human Research Ethics Committee for residents living permanently in any of the nine residential aged care facilities, with the cognitive ability to consent to be involved in the R-PAC Project. Although the Critical Reference Group was
keen to seek the involvement of residents and their families in the research process, their initial priority was to focus on tailored learning and development initiatives for aged care nurses and care assistants along with systems change. Given the direction that the R-PAC Project took as the action research process unfolded it became apparent that engaging residents and families in this process was beyond the scope of this particular study. Even though this is an important aspect of improving end-of-life care this area of research is fraught with difficulties\(^{56, 75}\). These challenges would have been amplified in the aged care setting where resident’s cognition and fragility would have impacted on the degree to which they could have engaged in the action research process. Despite these challenges, seeking residents and families’ involvement has been considered a priority for subsequent action research cycles. Consequently, consent was not sought from any residents or families to be engaged in the R-PAC Project.

As the design of the chart audit did not retrieve identifying resident information, consent was not required from the deceased residents’ next of kin or enduring guardian\(^{76}\). In addition to ethical approvals, written permission to conduct the audit was obtained from the necessary level of management within of the nine residential aged care facilities.

3.15 Data collection methods

A range of data collection methods are suited to the action research process in a health care environment, including: audits of medical records; surveys; focus groups; reviews of group records and minutes; and researcher’s personal reflective journal.

3.15.1 Retrospective chart audit

A prospectively designed chart audit, using selected outcome criteria determined by best practice guidelines\(^{71, 77}\) was used to examine the level and type of care provided to residents during the last 72 hours of life, at both baseline (Phase One, Study B) and twelve months following the implementation of the multifaceted intervention (Phase Four, Study H). A chart audit is said to be robust when used on a random sample of medical records with data yielded from this process previously being used to influence government policy and action by health care providers\(^{78}\). This methodology has been used extensively to improve patient safety by detecting deviations in appropriate standards of care and providing objective information about the consequence of that deviation that assists to better understand its causation\(^{16}\).
The documentation of the quality and type of end-of-life care provided to residents was assessed using a modified ‘Liverpool End-of-Life Base Review’ (Appendix 5)(79). This process has previously been used extensively in the acute, community and to a lesser extend in residential aged care settings in the United Kingdom(80, 81). This audit tool provided a standardised method of recording data which was designed to capture the level of palliative care provided to residents in the last 72 hours of life, including acknowledging dying, end-of-life communication, limiting unnecessary interventions, prescribing appropriate medications, providing appropriate nursing and spiritual care; and specific palliative care interventions. It was prospectively modified by the research team to collect additional information relating to the classes of medications used, level of engagement with the specialist palliative care team and to include a therapeutic intervention score(82). A Cronbach’s alpha of 0.724 has been reported for the modified ‘Liverpool End-of-life Base Review’ indicating an acceptable level of internal consistency and reliability(83).

The retrospective chart audits were completed by two nurse researchers with advanced clinical knowledge and extensive clinical experience - the researcher and the principal supervisor. Five sample chart audits were completed by each researcher and reviewed separately to establish inter-rater reliability. Results were compared and found to be in agreement more than 95% of the time, which is comparable to levels of agreement reported in a similar study(76).

The chart audits assisted with the mapping of changes over time and also aided in measuring the degree to which evidence based care, as promoted in the recently released Commonwealth Governments ‘Guidelines for a palliative approach in residential aged care’ had been adopted(71). Recommendations arising from this audit process provided opportunities to improve the systems of care in local residential aged care facilities(16).

3.15.2 Focus groups

Focus groups methodology is a form of group interview that generates rich interactive data about social phenomena through the opinions expressed by participants individually and collectively(84-86). During Phases One (Study C) and Three (Studies E and F) of the action research cycle, research participants were provided with an opportunity to take part in a series of focus groups. This methodology was chosen because it is a useful way of developing an understanding of participants’ perceptions and feelings about a particular issue, product,
service or idea\textsuperscript{(87, 88)}. Focus groups provide an opportunity for reflective interaction with others who may have complementary or differing views on an issue\textsuperscript{(84)}. The added advantage of using focus group methodology was that it placed the researcher in a less commanding and controlling role of information gathering, while actively engaging participants in a process that was focused on making a difference\textsuperscript{(87, 89)}.

However, as with all research methods there are some limitations with undertaking this type of data collection. A focus group introduces many participants which makes it an uncontrolled social situation where the researcher has limited control over the discussions which have the potential to become quite tangential\textsuperscript{(85)}. There is also the potential for some participants to dominate the conversations while others may not contribute at all. These interactions can also be affected by personal characteristics and social factors such as class, gender and race\textsuperscript{(85)}, which are important considerations given the composition of the aged care workforce. Addressing these issues required a combination of skilled moderation, attention to the composition of the groups, the question route and the environment where the focus groups are conducted.

The quality of the data is dependent upon the skills of the moderator\textsuperscript{(85)}. The moderators personal biases and ideas can easily and often unconsciously be communicated to the group via verbal and non-verbal cues\textsuperscript{(89)}. Therefore, an effective moderator requires exceptional communication skills, the ability to listen, lead a group and encourage participation\textsuperscript{(90)}, as well as being empathic, socially aware, flexible and assertive\textsuperscript{(85)}. These interpersonal skills are important as the moderator needs to be able to add to the depth and richness of the data by respectfully asking neutral questions, probing answers and encouraging dissenting views\textsuperscript{(91)}.

All of the focus groups were conducted in an environment and a time that best suited the participants and this action was an important initiative that aimed to create a safe environment that would promote the free and open exchange of participants\textsuperscript{(92)}. Prior to commencing each focus group cycle, a question route was developed as a way of inviting exploration of different views, solutions, suggestions and to help identify the strengths and resources that may be readily available. Care was taken not to ask leading questions, nor make suggestions which could influence the participant’s responses. A member of the research team facilitated each focus group while the assistant took detailed field notes, documented observations, interactions between groups of staff and notable quotes\textsuperscript{(91, 93)}. This allowed for the issues of
time and person to be included in the analysis\(^{93}\). Focus groups were conducted until it was apparent to that no new data were being generated.

The focus groups provided an opportunity for collective reflection and evaluation of each participant’s involvement in the R-PAC Project. Focus groups also facilitated identifying the group’s achievements, at a personal and organisational level, as well as the collective activities undertaken by the group. The data generated from these focus groups helped identify actions, including interventions, and informed evaluation strategies to be considered during the next iteration of the action research process\(^{10, 64, 94}\).

### 3.15.3 Survey

The survey instrument ‘*Tool 2.1: Palliative care providers’ views and attitudes*’, hereon referred to as Tool 2.1 was selected from the National Rural Palliative Care Tool Kit for use in this study (Appendix 6)\(^ {95}\). Tool 2.1 is an amalgam of selected sections from two separate survey instruments designed to measure aged care nurses\(^ {96}\) and physician confidence, clinical skills, and decision making at the end of life\(^ {97}\). This survey instrument has six separate sections relating to demographic details, providers views about palliative care, death and dying, attitudes towards palliative care, importance of caring issues and desire for future education (Table 3-2). A Cronbach’s alpha of 0.88 is reported for this sample using this survey instrument, indicating an acceptable level of internal consistency and reliability\(^ {83}\).

This 67 item survey is based on a predominantly structured and closed ended question format with scope for participants to add in additional learning needs. This survey was administered in person by the researcher to all study participants during Phase One (Study D) and at the conclusion of the R-PAC Project in Phase Four (Study F) to detect changes in participants knowledge, attitudes, beliefs and learning needs.
Table 3-2: Palliative care providers’ views and attitudes survey sections

<table>
<thead>
<tr>
<th>Sections</th>
<th>Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic details</td>
<td>Age, gender, Aboriginality, ethnic background, professional discipline and levels of previous palliative care training</td>
</tr>
<tr>
<td>Views about palliative care</td>
<td>Level of confidence in 12 patient/family interactions and clinical management issues (five levels: need further basic instruction, confident to perform with close supervision/coaching, confident to perform with minimal consultation, confident to perform independently).</td>
</tr>
<tr>
<td>Views about death and dying</td>
<td>Level of agreement with 10 statements related to death and dying (five levels: strongly agree, agree, unsure/mixed, disagree, and strongly disagree).</td>
</tr>
<tr>
<td>Attitudes towards palliative care</td>
<td>Level of agreement with 15 statements related to palliative care (five levels: agree strongly, agree, neither agree nor disagree, disagree, disagree strongly).</td>
</tr>
<tr>
<td>Importance of caring issues</td>
<td>Level of importance of 9 specific issues in terms of the problems they create in caring for a dying patient (five levels: very important, important, unsure, less important, and not important).</td>
</tr>
<tr>
<td>Future education requested</td>
<td>Nominated educational topics</td>
</tr>
</tbody>
</table>

During initial data collection (Study D) it was noted that there was substantial amount of data missing from the ‘discipline’ category, suggesting that this term may have been misunderstood by a number of participants. Subsequently, participants were informed that this question was seeking to determine their professional background and they were asked to state the award that they were employed under in aged care. The data obtained from the survey guided the development of the multifaceted intervention implemented during Phase Three.

3.15.4 Researcher’s reflective journal

The use of a reflective journal enabled the researcher to document different themes, issues and concepts that had arisen as part of the R-PAC Project’s action research process. This journal assisted the researcher to document the ongoing critique and self appraisal that occurred during this study. This reflective journal provided an account of the research development,
decision making and empowerment process that transpired during the R-PAC Project. This journal helped to provide a contextual understanding of the environments in which the action research process was occurring. It also captured the researcher’s own involvement in and reflections on the action research cycle, documented milestones in the project and processes by which issues and dilemmas were reconciled. In addition to the reflective journal, all electronic mail messages from the researcher and supervisor and other parties were stored to provide a background narrative of actions and reflections occurring during the action research process.

3.15.5 Reviews of group records and minutes

Minutes of all reference groups and attendance records provided data on issues raised at meetings, frequency of meetings and the number of participants. These documents provide a formal documented account of the R-PAC Project’s development, progress and the context in which various decisions were made.

3.16 Data analysis and methodological rigor

In this action research study, data analysis was undertaken as an ongoing iterative process. Although, both quantitative and qualitative data methods have been employed in this mixed methods research design, each has retained its essential characteristics and methodological considerations. This is reflected in the manner in which data analysis has been undertaken and reported. The qualitative data sets were initially analysed separately and systematically interrogated for emergent themes. Subsequently, as part of mixed methods, data sets were compared and contrasted. As each action research phase has been driven by the research findings this approach has been critical to maintaining the R-PAC Project’s momentum.

Throughout this study the researcher has been aware of the need for reflexivity and the use of a reflective journal has assisted with this process. While analysing the data, the researcher’s self-awareness and ability to engage in critical self reflection has been used as a strategy to minimise against potential biases and predispositions that may have affected the research process and subsequent findings. Negative case sampling was another strategy used by the researcher to mitigate against biases and this has involved critically examining the data for cases that do not confirm the researcher’s expectations and conflict with tentative explanations of the findings.
3.16.1 Quantitative data analysis

The quantitative data obtained from the questionnaire and the chart audits were entered into the Statistical Package for Social Science (SPSS) Version 14.0 to derive frequency estimates. Descriptive and correlation statistics were used with \( p < 0.05 \) being taken to indicate statistical significance. All of the quantitative data reported in this thesis have been verified by a statistician and further detail is provided in relevant chapters.

3.16.2 Qualitative data analysis

Qualitative data collection and analysis were undertaken concurrently as reflexive activities. All qualitative data were analysed according to thematic content analysis stages described by Burnard\(^{100}\) (Refer Figure 2-4). In addition, following each of the focus groups the researchers met to reflect on group interactions, in particular non-verbal clues endorsing values, opinions and beliefs. The focus groups continued until it was agreed by the researcher and principal supervisor that no new information was emerging and that data saturation had been attained\(^{90, 101}\). Transcripts allowed for the data to be categorised before undergoing further revision, grouping and reduction, with the final category coding of the broad analytic themes being confirmed with study participants\(^{100, 102, 103}\).

In accordance with the action research process, each phase of this study involved negotiating the outcomes with research participants to verify whether they considered the interim and final research outcomes an accurate portrayal of their lived experience\(^{104}\). All outcomes were evaluated for their credibility, transferability, dependability and conformability through data verification and member checking. Issues encountered during the course of data collection will be discussed in depth in Chapter’s Four, Six and Seven.
3.17 Data management

The data obtained throughout the R-PAC Project was recorded, handled and stored in a way that best allowed its accurate reporting, interpretation and verification. Surveys, interview and field notes and audio-tape recordings have been kept in a locked filing cabinet. During the study, no identifying data were obtained from participants completing the survey, focus groups or during the chart audits. The confidentiality of the research participants has been protected, while respecting the privacy and confidentiality rules of the applicable regulatory authority and the facilities involved in the study. Publication of the research findings only includes de-identified data to protect the privacy and confidentiality of all participants involved in this research. All data were collected and managed in accordance with Commonwealth Privacy Act (1988)\(^{(105)}\) and NSW Privacy Legislation (2003)\(^{(106)}\) requirements with access restriction authorisations including access to paper based research material and data (under secure storage), and computerised access level restrictions. All electronic documents related to the study are under password control and held securely at the Mid North Coast Division of General Practice, High Street, Coffs Harbour. These data will be stored securely for a minimum of 5 years before being destroyed.
3.18 Limitations of the action research method

The action research process was considered to be the methodology most likely to promote the delivery of a palliative approach, whilst engaging aged care nurses and care assistants in a change process that was educational, empowering and emancipating. At the outset of the study it was acknowledged that using this research approach with its absence of a control group, the heterogeneity of the intervention and the presence of a large number of extraneous variables would limit this study’s extrapolation to other settings. These factors would also impede the ability to confirm whether any observed improvements were directly attributable to the intervention.

The R-PAC Project design endeavoured to mitigate against these potential limitations by measuring trends and changes in nurses and care assistants palliative care competencies and confidence by administering ‘Tool 2.1: Palliative care providers’ views and attitudes’ during Phases One (2004) and Four (2006). Focus groups have been conducted during the commencement of Phase One to collect baseline data (2004) and repeated after the implementation of the multifaceted intervention to measure perceived changes during Phase Three (2005). While the retrospective chart audit data was not intended to ascribe causality it was used to identify trends, generate hypotheses and provide a greater insight into the end-of-life care provided in the nine residential aged care facilities at two points in time: at baseline and prior to the commencement of the R-PAC Project (2003) and following the implementation of the multifaceted intervention at the commencement of Phase Four (2005).

It is acknowledged that a palliative approach is more than just end-of-life care, but in the absence of specific palliative approach instruments, more generic palliative care tools were selected for data collection. It was also considered that the tools selected would reflect the way in which residents’ symptoms and palliative care needs were usually managed and the degree to which specialist palliative care services had input into the management of residents’ complex care needs, all of which are integral to the delivery of a palliative approach. In addition, end-point data such as number of deaths managed within the facility are seen as surrogates for aged care nurses and care assistants palliative care confidence to manage residents’ deaths and has been used as outcome data.

The eight sub studies conducted as part of the R-PAC Project have all been analysed separately and the findings from each of these present a unique aspect of the project under
consideration\textsuperscript{(52)}. The data obtained during each phase have informed subsequent phases of the action research process.

3.19 Conclusion

The R-PAC Project evolved out of recognition of unmet palliative care need of older people in residential aged care facilities and aged care nurses and care assistants desire to enhance the delivery of a palliative approach in their workplace. Although a range of methodological approaches were available and despite the challenges described above, this study adopted an action research process. It was considered that action research would be the most effective in engaging health care providers in nine residential aged care in a process that was both empowering and which offered the greatest potential to improve the delivery of a palliative approach\textsuperscript{(1, 2)}. The R-PAC Project has used mixed methods which have been described in this chapter. The following chapter provides a discussion of the baseline end-of-life chart audit, nurse and care assistant’s survey and focus group perceptions and needs. This data informed the development of the multifaceted intervention which is detailed in Chapter Five.
3.20 Reference list


32. Lather, P. (2002). 'What will have been said and done?' *Qualitative Social Work, 1*(1), 131-5.


64. van Eyk, H., & Baum, F. (2003). Evaluating health system change - Using focus groups and a developing discussion paper to compile the "voices from the field". *Qualitative Health Research, 13*(2), 281-6.


CHAPTER THREE


Chapter 4.

Diagnostic Phase: Developing

Priorities for Action
‘History is a guide to navigation in perilous times. History is who we are and why we are the way we are’. David McCullough

4.1 Introduction

Until recently Australian aged care policy and practices have been directed towards promoting quality of life in a home like environment\(^1\). However, as discussed in Chapter One, population ageing, biomedical advances, escalating health care costs, a shortage of acute care beds and changing societal values\(^2-5\) are challenging the way in which health care is provided to older people in residential aged care facilities\(^3, 6, 7\). These changes mean that the majority (86%) of older people admitted to residential aged care in Australia will live out their remaining days in this care setting\(^8\), or transferred to hospital, before dying from complications primarily related to non-malignant diseases\(^9, 10\). Currently, one in five older people in the UK\(^11\) and Australia\(^8\), and one in four in the USA\(^12\) die in aged care facilities. The increasing levels of frailty, disability and complex and chronic diseases experienced by older people admitted to permanent care in the developed world, has compelled governments to address this health care challenge\(^6, 13, 14\). In the UK this has prompted the development of regulatory frameworks and policy papers\(^15\), including promoting the use of the Gold Standards Framework\(^11\), Preferred Place of Care\(^16\) and Liverpool Care Pathway to enhance end-of-life care in aged care facilities\(^17\). Australian public policy and evidence based guidelines have recommended that delivery of a palliative approach for aged care residents is required because of their frailty and or chronic and complex disease progression\(^6\). The ‘Guidelines for a palliative approach in residential aged care’ represent a synthesis of expertise from geriatrics, gerontology and palliative care\(^18\). These guidelines managed to sensitively fuse aspects of these discrete disciplines to develop an evidence based population framework for palliative aged care delivery\(^18\). These guidelines reinforce that a palliative approach is indicated throughout the residents care trajectory\(^6\), rather than being reserved solely for end-of-life care and that, on occasions, residents with complex symptom control problems will require specialist palliative care input\(^19\). Whilst dying, residents managed in the aged care setting require access to timely and appropriate end-of-life care\(^6\). The emergence of this new care paradigm has generated significant interest from clinicians, academics and researchers\(^20\).

In spite of the increased interest in a palliative approach, at the commencement of the R-PAC Project in 2004, little was known about the ability and capacity of aged care personnel to function within this new management paradigm. This chapter reports the findings of three
discrete, yet linked studies. These studies were undertaken during Phase One of the R-PAC Project’s action research process to identify facilitators and barriers for the delivery of a palliative approach in the residential aged care setting. The overarching methodological considerations related to these studies have been outlined in Chapter Three.

A focused chart audit (Study B) was undertaken to identify the level of palliative care provided to dying residents at baseline. A series of focus groups (Study C) were undertaken to investigate the perceptions and beliefs about palliative care amongst nurses and care assistants working in local aged care facilities. A survey (Study D) to document the views and attitudes of aged care personnel towards palliative care and to identify their learning needs was also administered. The data from these three studies have informed the development of a multifaceted intervention to promote the delivery of a palliative approach using a population focus in Coffs Harbours’ nine local residential aged care facilities, which is described in Chapter Five.

4.2 Study B: Chart audit to determine factors in end-of-life care

Death has increasingly become institutionalised with the majority of people receiving their end-of-life care in either the acute care setting or within residential aged care facilities\(^{12}\). As reported in Chapter Two, the nine residential aged care facilities in Coffs Harbour during 2003 collectively cared for 169 residents who died, the majority (79%) of these people receiving their end-of-life care within the facility. End-of-life care has been defined as the ‘...period preceding a person’s natural death that is unlikely to be arrested by medical care’\(^{21}\) (p.S12). Despite high rates of mortality within aged care, methodological challenges in undertaking clinical trials, prognostication, respondent burden and issues related to non-response have effectively limited the number of studies that have focused on measuring the experiences and outcomes of people dying in this setting\(^{22-26}\). In an effort to overcome some of these issues, previous palliative care studies have used a chart audit to gain insights into care practices at the end-of-life\(^{27}\). This research method has also been used extensively to improve patient safety and quality by reviewing the delivery of care against known or best practice to identify and remedy care deficiencies\(^{28, 29}\). The validity of the chart audit method is increased when strategies are undertaken to eliminate bias, such as the use of random samples or prospective, consecutive cases\(^{30}\).

Due to the small study population and restrictive time windows, prospective consecutive charts were reviewed for the R-PAC Project. The Critical Reference Group considered that a
chart audit focusing on the last 72 hours of care provided to deceased residents and their families would provide a snapshot of the level of palliative care being provided within local aged care facilities. Although it is acknowledged that a palliative approach is more than terminal care, it was felt that this audit data could act as an indicator for overall palliative care delivery within the local aged care facilities. Further, these data would provide some insight into the palliative care practices in operation, aged care personnel’s palliative care symptom management competencies and assist in determining their level of comfort with dealing with death and dying.

4.2.1 Aim

The aim of the chart audit was to assess the level of palliative care provided to dying residents and their families in the last 72 hours of life in Coffs Harbour’s nine residential aged care facilities. 

4.2.2 Design

A prospectively designed chart audit was used to examine the level and type of palliative care provided to residents during the last 72 hours of life (Appendix 5). The ‘Liverpool End-of-Life Base Review’ (29) was modified to measure the level of palliative care provided to residents in the last 72 hours of life (Appendix 7). This audit tool has been widely used in a variety of care settings in the UK to assess end-of-life care (27, 32), including residential aged care (14, 33). As part of this modification for local purposes, the classes of medications used, number of admissions to acute care in the previous 12 months; and a therapeutic intervention score were added (34).

4.2.3 Sample

All residents who died in the nine residential aged care facilities during the last quarter of 2003 were eligible for inclusion in the chart audit (31). Residents who died in hospital were excluded from the study.

Ethical approval was obtained from the HREC, who considered that a chart audit was a quality activity and as the audit tool design did not retrieve identifying resident information, consent was not required from the deceased residents’ next of kin or enduring guardian(s) (24). The resident’s unit record number was recorded to enable cross checking to be undertaken. In
addition to ethical approvals, written permission to conduct the audit was obtained from the necessary level of management within the nine residential aged care facilities (Appendix 8).

4.2.4 Data analysis

Data were entered into the Statistical Package for Social Science (SPSS) Version 14.0 to derive frequency estimates. All data have been reviewed and confirmed by a statistician.

4.2.5 Findings

Thirty eight deceased residents’ aged care medical records met the inclusion criteria and were reviewed. The majority of deceased residents in this audit were females (61%, \( n=23 \)) with a mean [SD] age of 84 [SD ± 9.5] years. Resident’s deaths were primarily related to complications from either cardiovascular disease (31%, \( n=12 \)) or fragility (29%, \( n=11 \)) (Table 4-1).

**Table 4-1**: Residents’ primary and secondary diagnoses at the time of death\(^{(31)}\)

<table>
<thead>
<tr>
<th>Primary diagnosis</th>
<th>Secondary diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>( n=38 ) (100)</td>
<td>( n=38 ) (100)</td>
</tr>
<tr>
<td>Malignancy</td>
<td></td>
</tr>
<tr>
<td>6 (16)</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td></td>
</tr>
<tr>
<td>6 (16)</td>
<td>20 (53)</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td></td>
</tr>
<tr>
<td>12 (31)</td>
<td>22 (58)</td>
</tr>
<tr>
<td>Respiratory disease</td>
<td></td>
</tr>
<tr>
<td>2 (5)</td>
<td>8 (21)</td>
</tr>
<tr>
<td>Neurological condition</td>
<td></td>
</tr>
<tr>
<td>1 (3)</td>
<td>18 (47)</td>
</tr>
<tr>
<td>Fragility</td>
<td></td>
</tr>
<tr>
<td>11 (29)</td>
<td>25 (66)</td>
</tr>
<tr>
<td>Musculoskeletal conditions</td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>12 (32)</td>
<td></td>
</tr>
<tr>
<td>Other conditions</td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>22 (58)</td>
<td></td>
</tr>
</tbody>
</table>

Total responses >100% indicate more than one secondary diagnosis

Not applicable (N/A)
For this audit, fragility was defined as ‘…a syndrome of weakness, fatigue, and weight loss…which contributes to a host of consequences and poor outcomes’\(^{(35)}\) (p.94). A smaller proportion of resident’s deaths were directly attributed to malignancy (16%, \(n=6\)) and complications from advanced dementia (16%, \(n=6\)). There were high levels of co-morbidity, with two thirds of residents known to have cardiovascular disease (58%, \(n=22\)), while almost half (47%, \(n=18\)) had an existing neurological condition, such as Parkinson’s disease or a hemiplegia following a cerebral vascular accident. Over half (53%, \(n=20\)) of the residents at the time of death had some degree of cognitive impairment.

**4.2.6 Hospital admissions**

In the 12 months preceding their death, 45% (\(n=17\)) of residents were admitted to acute care, with the mean (SD) admission period being 6.68 days [SD ± 12.42]. Overall, there were 0.97 admissions [SD ± 1.64] per resident to acute care facilities in the 12 months prior to death.

**4.2.7 Medication management**

As detailed in Figure 4-1, the majority of residents (74%, \(n=28\)) were still swallowing 72 hours prior to death but this fell at 24 hours to 55% (\(n=21\)). At 72 hours, 4.57 medications [SD ± 2.6] were being used by residents with this number reducing to 3.9 [SD ± 2.7] medications at 24 hours. A third (32%, \(n=12\)) of residents had their non-essential medications ceased at 72 hours. Non-essential medications were defined as those medications given for long-term disease prevention and health maintenance\(^{(29)}\). Analgesics were the most commonly prescribed and administered medication (84%, \(n=32\)) at 72 hours, followed by cardiovascular medications (42%, \(n=16\)).

**4.2.8 Symptom management**

There was documented evidence of residents experiencing 1.38 symptoms [SD ± 0.96] at 72 hours (Figure 4-2), with pain (63%, \(n=24\)) being the most commonly noted symptom (Figure 4-3).
Figure 4-1: Swallowing and medications in use 72 hours before death

Figure 4-2: Number of symptoms experienced by residents 72 hours before death
Figure 4-3: Type of symptoms experienced by residents 72 hours before death

The majority (84%, n=32) of residents had an analgesic orders at 72 hours prior to death (Figure 4-4). Simple analgesics (non-opiates) were the most commonly prescribed analgesia (58%, n= 22) followed by opiates (53%, n=20). The opiate orders included, regular oral opiate which were prescribed for half (53%, n=20) of the residents, regular subcutaneous (S/C) opiate which were ordered for a third (34%, n=13) of residents; and PRN subcutaneous opiate orders which was ordered for a quarter (26%, n=10) of residents.
Pain was reported for almost two thirds (63%, n=24) of the residents in the audit sample. The majority (80%, n=19) of residents with pain received regular analgesics (Figure 4-5). Despite this analgesic cover, over half of the residents with pain (50%, n=12) experienced episodes of uncontrolled pain in the last 72 hours. A quarter (25%, n=6) of residents with breakthrough pain were given PRN analgesia. Few residents with pain (16%, n=4) had their pain regularly assessed and there was no charts that provided evidence of the use of a validated pain assessment tool.

Dyspnoea was the second most common symptom experienced by almost a fifth (24%, n=9) of all residents during the last 72 hours (Figure 4-3). A third (33%, n=3) of residents with dyspnoea were using oxygen at this time (Figure 4-6). There was no documented evidence of PRN opiates or anti-anxiety agents being used to manage residents’ dyspnoea at the end-of-life. A small number (10%, n=4) of residents experienced excessive respiratory tract secretions at 72 hours. Further, there was no documented evidence of a PRN subcutaneous anticholinergic being prescribed to manage this symptom at 72 hours. However, at 24 hours an anticholinergic was ordered regularly for one (25%) resident who experienced excessive respiratory tract secretions.
Data derived from the chart audit showed that restlessness and agitation was the third most common symptom, experienced by 18% \( (n=7) \) of residents (Figure 4-3). Almost a third (29%, \( n=2 \)) of residents with this symptom had their restlessness assessed, but there was no evidence of other causes of restlessness and agitation being considered (Figure 4-7). Sedation
was given to manage restlessness and agitation in the last 72 hours for a small number (14%,\(n=1\)) of these residents. Only a small minority of residents (16%,\(n=6\)) experienced confusion and delirium, making it the fourth most common symptom (Figure 4-3). A small number of residents (17%,\(n=1\)) were administered an antipsychotic to help manage their confusion.

![Figure 4-7](image_url)

**Figure 4-7:** Management of restlessness/agitation and confusion/delirium in last 72 hours before death

A small number of residents experienced nausea and vomiting (11%,\(n=4\)). The majority of these residents (75%,\(n=3\)) had their nausea and vomiting regularly assessed and all were provided with a regular anti-emetic (100%,\(n=4\)). There was no documented evidence of any residents receiving any form of artificial hydration.

### 4.2.9 Nursing care

Documentation revealed that these residents received high quality nursing care with attention being paid to regular mouth care, hygiene, pressure area care, bowel management and assessment of voiding as detailed in Table 4-2. Pressure relieving devices were provided to a small number of residents (18%,\(n=7\)). There was limited use of indwelling catheters (3%,\(n=1\)), with incontinence pads being used for the majority of residents (79%,\(n=30\)). Chart audits revealed that 10% (\(n=4\)) of residents required wound management in the last 72 hours.
Table 4-2: Level of nursing care provided

<table>
<thead>
<tr>
<th>Sample</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular mouth care</td>
<td>34</td>
<td>(90)</td>
</tr>
<tr>
<td>Assessment of voiding</td>
<td>28</td>
<td>(74)</td>
</tr>
<tr>
<td>Use of indwelling catheter</td>
<td>1</td>
<td>(3 )</td>
</tr>
<tr>
<td>Use of incontinence aids – pads</td>
<td>30</td>
<td>(79)</td>
</tr>
<tr>
<td>Use of pressure relieving devices</td>
<td>7</td>
<td>(18)</td>
</tr>
<tr>
<td>Regular pressure area care</td>
<td>33</td>
<td>(87)</td>
</tr>
<tr>
<td>Wound care</td>
<td>4</td>
<td>(10)</td>
</tr>
<tr>
<td>Bowel care plan in place</td>
<td>37</td>
<td>(97)</td>
</tr>
</tbody>
</table>

4.2.10 Palliative care provided

Documentation revealed that although half (53%, n=20) of the residents were aware of their diagnosis, very few residents were aware that they were dying (16%, n=6) (Table 4.3). The majority of residents’ families were informed of the resident’s impending death (66%, n=25) and the plan of care discussed with the family (60%, n=22). The majority (68%, n=26) of general practitioners were informed of the resident’s deterioration with well over half (60%, n=23) of the residents being reviewed by their general practitioner in the last 72 hours of life. Few residents (5%, n=2) had a specialist palliative care consultation or their care or treatment planned by a multidisciplinary team (8%, n=3). An aged care multidisciplinary team consists of a number of health and welfare disciplines, with all team members working collaboratively to ensure an integrated approach to treatment and care decisions(19). A regular care planning meeting is an essential element of effective multidisciplinary care(36,37).

Over two thirds (68%, n=26) of the residents had their spiritual care needs assessed. The majority (97%, n=37) of residents were provided with what was classified as comfort care which is defined as medical and nursing care focusing on pain control, including the use of a syringe driver, access to social services and psychological support from nursing staff(34) (Table 4-4).
### Table 4-3: Level of palliative care provided

<table>
<thead>
<tr>
<th>Sample</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reviewed by specialist palliative care team</td>
<td>2</td>
<td>(5)</td>
</tr>
<tr>
<td>Multidisciplinary care planning meeting</td>
<td>3</td>
<td>(8)</td>
</tr>
<tr>
<td>Reviewed by GP in last 72 hours of life</td>
<td>23</td>
<td>(60)</td>
</tr>
<tr>
<td>Resident aware they are dying</td>
<td>6</td>
<td>(16)</td>
</tr>
<tr>
<td>Family aware resident is dying</td>
<td>25</td>
<td>(66)</td>
</tr>
<tr>
<td>Resident’s plan of care discussed with family</td>
<td>22</td>
<td>(60)</td>
</tr>
<tr>
<td>GP aware the resident is dying</td>
<td>26</td>
<td>(68)</td>
</tr>
<tr>
<td>Identification of how family are to be contacted</td>
<td>31</td>
<td>(82)</td>
</tr>
<tr>
<td>Resident’s spiritual needs assessed</td>
<td>26</td>
<td>(68)</td>
</tr>
<tr>
<td>GP contacted regarding the resident’s death</td>
<td>38</td>
<td>(100)</td>
</tr>
<tr>
<td>Family informed of the tasks following death</td>
<td>34</td>
<td>(90)</td>
</tr>
</tbody>
</table>

### Table 4-4: Level of care provided

<table>
<thead>
<tr>
<th>Sample</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Died before anything done</td>
<td>1</td>
<td>(3)</td>
</tr>
<tr>
<td>Comfort care provided</td>
<td>37</td>
<td>(97)</td>
</tr>
<tr>
<td>Moderate level care</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td>High level care</td>
<td>0</td>
<td>(0)</td>
</tr>
</tbody>
</table>

Source: Adapted Therapeutic Intervention Score, Lowe and Kerridge

Although cardio-pulmonary resuscitation could be considered inappropriate for older people who live permanently in a residential aged care facility, none of the facilities involved in the R-PAC Project had a documented resuscitation policy. A quarter (24%, $n=9$) of residents in the audit sample had a documented ‘do not resuscitate’ (DNR) order. The scope of these DNR orders was only clearly defined for 13% ($n=5$). A third of residents had a ‘do not transfer to hospital’ order (34%, $n=13$) and evidence of an advance care plan (34%, $n=13$) at the time of their death (Table 4-5).
Table 4-5: End-of-life care preferences

<table>
<thead>
<tr>
<th>Sample</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documented ‘do not resuscitate’ order</td>
<td>9</td>
<td>(24)</td>
</tr>
<tr>
<td>Scope of ‘do not resuscitate’ orders defined and documented</td>
<td>5</td>
<td>(13)</td>
</tr>
<tr>
<td>Discussion of ‘do not resuscitate’ order with family</td>
<td>3</td>
<td>(8 )</td>
</tr>
<tr>
<td>Discussion of ‘do not resuscitate’ order with residents</td>
<td>10</td>
<td>(26)</td>
</tr>
<tr>
<td>Documented advance care plan</td>
<td>13</td>
<td>(34)</td>
</tr>
<tr>
<td>Documented ‘do not transfer to hospital’ order</td>
<td>13</td>
<td>(34)</td>
</tr>
</tbody>
</table>

4.2.11 Discussion

The residents profiled in this audit are typical of the current Australian residential aged care population where the majority of residents are of advanced age, female, have some degree of cognitive impairment and died from complications related to non-malignant diseases and fragility\(^6, 7, 38\). Although, this finding concur with other studies that have found that advanced dementia and cardiovascular disease are the main cause of resident’s terminal status\(^23, 24, 38\), this study also found cancer caused as many deaths as cognitive impairment. This finding reflects that the incidence of cancer increases with age, with 44% of all patients being aged over 70 years at diagnosis\(^39\). Not surprisingly the number of residents who were aware that they were dying was very low, which reflects the high levels of cognitive impairment in this sample. Cognitive impairment limits the degree to which aged care personnel or the general practitioner can engage in an end-of-life conversation with the resident.

The high levels of fragility observed in this study are in keeping with the underlying pathophysiology of death in people with a life limiting illness, where deaths usually results from systemic changes as opposed to single organ failure\(^40\). These changes contribute directly to weight loss, anorexia and fatigue\(^41\) which typify end stage disease and was observed in this audit\(^40\). The level of symptom burden of dying residents reported in this study is less than that the three or more symptoms reported by Hall and colleagues\(^24\). This variation may reflect the underlying disease which may determine the patterns of symptoms\(^23\), particularly as this elderly resident cohort largely died of non-malignant disease and whose care didn’t
dictate transfer to the acute care setting. Alternatively, it may reflect the audit tool that was initially designed to measure the level of palliative care provided to people dying of malignancy as opposed to advanced aged and chronic and complex diseases\(^{(29)}\), or it may reflect poor documentation.

As expected there were low levels of medical intervention amongst this sample of residents with a focus on comfort care. The delivery of appropriate end-of-life care requires judicious planning and ongoing assessment. Therefore, it is of concern that only two thirds of these residents were reviewed by the general practitioner in the last 72 hours of life, particularly given the low levels of advance care planning and multidisciplinary team care planning evident in the resident’s clinical records. Further, as the general practitioner is the prime provider of medical care for older people it is difficult in the aged care setting to implement appropriate interventions in the absence of a recent medical assessment, adequate care planning and appropriate medication orders\(^{(42)}\). Accessing necessary symptom management medications at short notice for residents can be challenging in the residential aged care setting\(^{(33, 37)}\). This challenge is amplified after-hours and in regional aged care settings where there can often be delays in the delivery of pharmaceuticals and limited or no access to an impress supply of medications\(^{(37)}\). All of these factors suggest that enhanced multidisciplinary care planning is a precondition for good end-of-life care in the aged care sector\(^{(43)}\).

Of note, over half of these residents experienced pain in the last 72 hours of life, which is similar to that reported for older people dying in both the acute care\(^{(24)}\) and aged care settings\(^{(44)}\). Although the majority of residents had an analgesic order, only half of these orders were for an opiate and fewer orders were for regular opiate administration. As effective pain management is an essential component of end-of-life care it is of considerable concern that there was so little evidence of pain being assessed in a systematic manner, using a validated pain assessment tool. Given this reality the real number of residents in this audit who actually experienced pain, but whose pain wasn’t adequately documented may have been much higher than was identified. The infrequent use of a regular pain assessment tool and associated documentation is particularly troublesome given the high levels of cognitive impairment noted in this population\(^{(45-47)}\). This finding is similar to another study that found the majority of nursing homes do not use a standardised pain assessment tool\(^{(48)}\). Previous research has also found that residents’ complaints of pain frequently go unrecognised or are not properly addressed with either pharmacological and/or non-pharmacological interventions\(^{(45, 49)}\).
Dyspnoea is a distressing symptom and effective management is dependent upon regular assessment and planning\(^6\), but in this audit there was little evidence of this occurring. Despite, oxygen therapy being frequently used there was little evidence of the use of opiates or anti-anxiety agents to relieve the distress associated with dyspnoea. Excessive respiratory secretions are also common at the end-of-life\(^{29}\). Although, families and caregivers are frequently unsettled by the sound of excessive respiratory secretions, the person at the end-of-life is rarely aware of this symptom\(^{50}\). The management of excessive respiratory secretions is reliant upon repositioning and the use of anticholinergic agents, which was minimally observed to have been used in this audit. Restlessness and agitation are also common end-of-life symptoms that have a variety of underlying physical causes, such as distended bladder, full rectum, dyspnoea, biochemical imbalance (raised calcium, low haemoglobin or uraemia) and febrile due to infection\(^{50}\). Assessing for these underlying causes enables appropriate interventions to be implemented and helps minimise the resident’s and family’s discomfort and distress. There was little evidence in the audit that these alternative causes of the resident’s restlessness were considered, suggesting that this symptom may be viewed as a normal dying process for which little can be done to relieve this distress. Alternatively, as aged care personnel are frequently exposed to restless and agitated residents they may have become desensitised to this symptom, but this requires further investigation.

In this study, the reduction in medications used at 24 hour prior to death reflects the resident’s deteriorating status. Of note, over half of the residents were still able to swallow 24 hours prior to their death, suggesting that these residents were still conscious. The resident’s conscious state may have delayed the cessation of non-essential medications, which only occurred for half of the residents who died. Being consciousness and able to swallow may have clouded the identification of imminent death in these frail elderly residents, whose decline had occurred over a prolonged period and mirrors the organ/system failure and dementia trajectories described by Lynn\(^{51}\) and previously discussed.

All of these deceased residents received high quality nursing care in the last 72 hours of life, such as incontinence management, mouth care, hygiene and pressure area care. However, very few residents had their care reviewed by the specialist palliative care team or had their care planned by a multidisciplinary team. Overall there was little evidence of an integrated team approach to care planning or delivery. This study also found poor documentation of residents’ end-of-life care preferences with little evidence of a systematic approach being employed, which is similar to findings reported elsewhere\(^{44}\).
4.3 Implications for the action research process

The data obtained from the chart audit process described above confirmed the needs assessment findings reported in Chapter Two that older people in residential aged care had unmet palliative care needs, particularly related to management of pain, dyspnoea, restlessness and agitation and excessive respiratory secretions. There was compelling evidence that greater attention to comprehensive symptom assessment, use of appropriate pharmacological interventions and greater communication with the specialist palliative care team would enhance the resident’s comfort at the end-of-life. In addition, there was evidence to suggest that documenting a resident’s end-of-life care wishes in a systematic manner would help to reduce some of the ambiguity around the goals of care.

4.3.1 Sharing the data and navigating a pathway forward

The findings from the chart audit were shared with aged providers in each facility, the Critical Reference Group, Aged Care Professionals Group and the Project Advisory Group. Following a period of reflection and discussion about the implications of these data, it was determined that the next phase of the action research process ought to focus on enhancing aged care nurses’ and care assistants’ palliative care knowledge, skills and confidence. Although this was seen as the first critical step towards addressing the unmet palliative care needs of older people dying in residential aged care facilities, it was also considered to be important to systematically discuss these issues with aged care nurses and care assistants.

The complexity of the aged care environment, the diversity in clinical skills and workforce education levels, combined with resident’s medical care being provided by numerous general practitioners, suggested that an intervention providing information, knowledge and skills was required to increase the palliative care confidence and profile of residential aged care personnel. However, before developing this intervention more information was required about the palliative care perceptions of aged care nurses and care assistants working in these care settings and to determine their ideas about strategies to improve service delivery.

4.4 Study C: Focus group to reveal perceptions

A series of focus groups were organised to explore issues related to the delivery of palliative care in residential aged care\(^{(52)}\). These focus groups were conducted during Phase One of the
Chapter Four

R-PAC Project’s action research process to provide greater insights into the significance of palliative care delivery in local residential aged care facilities.

4.4.1 Aim

The aim of the baseline focus groups was to investigate the perceptions and beliefs about palliative care amongst nurses and care assistants working in Coffs Harbour LGA.

4.4.2 Design

Focus groups were used in this exploratory descriptive study.

4.4.3 Participants

All aged care nurses and care assistants employed in the nine local residential aged care facilities in Coffs Harbour were invited to contribute to one of four focus groups. An open invitation was sent to all residential aged care facilities inviting interested aged care personnel to join in one of four focus groups scheduled to be conducted during June 2004.

Sixty people volunteered, and the initial focus group consisted entirely of senior nurse managers from local residential aged care facilities (n=10). The findings from this group helped to shape, inform and drive the subsequent focus groups, which consisted of a combination of registered nurses (n=16), enrolled nurses (n=9) and care assistants (n=25).

4.4.4 Ethical considerations

Approval for the focus group study was obtained from the university HREC (Appendix 3). In addition, permission was obtained from all of the four aged care managers whose facilities were to be used as a venue for the focus groups. All focus group participants were provided with verbal and printed information relating to consent, confidentiality and withdrawal from the study before written consent was obtained (Appendix 4). Participants were also informed of several ethical issues related to protecting their privacy and confidentiality. The open discussion format of focus groups meant that all contributions would be inevitably heard by all of the participants and the researcher had limited control over what happened to this information outside of the group setting (53). All participants were asked not to disclose the experiences shared by other members of the group. This was discussed at the commencement and reiterated at the conclusion of each focus group. In addition, participants were referred to
only by their first names during the focus groups and assigned a unique code, only known to the researcher, which has been throughout the reporting of the data.

4.4.5 Data collection

As discussed in Chapter Three, groups represent complex phenomenon, with a tendency for some participants to reveal more in discussion with others than in an individual situation\(^{(54)}\). The stimulation of interaction and discourse between participants and the researcher is critical to the focus group process. Therefore, the creation of a safe environment for the free and open exchange of participant’s opinions is an obligatory prerequisite for focus group research\(^{(55)}\). This makes the exploration of attitudes collectively rather than individually a useful process, which aids in the examination of the social, organisational and environmental contexts of nursing practice\(^{(56)}\).

In order to derive systematic clinical change, it is useful to examine opinions, values and beliefs in the context of the practice that is undertaken\(^{(57)}\). Focus groups have also been reported to be an effective methodology to guide the development of interventions and ensure that the needs of consumers are addressed\(^{(58)}\). Participating in a focus group can often be an empowering experience, particularly when participants are involved in a process that they feel can make a difference\(^{(59)}\). Utilising this method was particularly suitable at the start of this action research project given that empowerment of aged care nurses and care assistants to feel more confident to delivery a palliative approach was a desired outcome of the R-PAC Project.

The question route for these focus groups was designed to allow exploration and probing of key issues defined from a literature review, needs assessment\(^{(60)}\) and local key informant interviews (Table 4-6).

A moderator (supervisor) facilitated each focus group, while an assistant moderator (researcher) took on the role of observer and scribe, paying particular attention to participant interaction and notable quotes\(^{(61)}\). The researcher was known to some of the participants, mainly the directors of nursing, through a previous role as a palliative care clinical nurse consultant. All of the focus groups were conducted in local residential aged care facilities and audio taped, to allow data verification and validation.
Table 4-6: Focus Group Questions - aged care personnel

<table>
<thead>
<tr>
<th>Question route</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does the term a palliative approach mean to you?</td>
</tr>
<tr>
<td>How do you think palliative care is different to the care you deliver as part of your daily practice?</td>
</tr>
<tr>
<td>What are some of the challenges to providing a palliative approach within your facility?</td>
</tr>
<tr>
<td>What are some of the factors that facilitate the delivery of a palliative approach within your facility?</td>
</tr>
<tr>
<td>Are there any other issues that you wish to raise?</td>
</tr>
</tbody>
</table>

4.4.6 Data analysis

Data collection and analysis were undertaken concurrently as reflexive activities\(^{(20)}\). Following each of the focus groups the moderator and assistant moderator met to reflect on group interactions, in particular non-verbal clues endorsing values, opinions and beliefs. At the conclusion of the fourth focus group it was agreed by the research team that no new information was emerging and that data saturation had been attained. The thematic content analysis process as described in Chapter Three, highlighted significant themes and concepts\(^{(62)}\). The use of transcripts allowed for all of the data to be categorised before undergoing further revision, grouping and reduction\(^{(62)}\). The final category coding of the broad analytic themes were shared and confirmed with study participants\(^{(62)}\).

4.4.7 Findings

The analysis of six hours of transcribed data revealed four broad analytic themes: (1) Being like family (2) Advocacy as a key role (3) Communication challenges and (4) Battling and striving to succeed against the odds\(^{(20)}\).

Being like family

The strong relationship and genuine bonding between aged care personnel and residents was evident in both dialogue and non-verbal cues and this was also demonstrated in the participants’ description of the need to protect and care for residents, not unlike the care they would provide a family member: ‘We do care’ (care assistant, group 2) and ‘we only want the
best for them' (enrolled nurse, group 4) and another comment, ‘This is their home, this is where they should be cared for’ (care assistant, group 3). Although there was a strong sense of the resident being ‘like family’, the participants saw that the emphasis of documenting routine care was ‘robbing’ them of time with the resident, particularly when much of the documentation as a result of recent policy reform\(^{(63)}\) was perceived as being largely repetitive and redundant. It has been previously suggested that this restructuring was forcing aged care nurses to be more focused on paper work regulatory and reporting issues as opposed to hands on care\(^{(64)}\).

For these participants there was also a sense of frustration that their workloads often prevented them from being with the resident during times of need, especially if the resident was ‘dying alone’. There was a perception amongst the participants that if this occurred then they weren’t doing enough for the resident, as they wouldn’t permit a member of their own family to die alone. This concept of ‘not doing enough’ has been previously acknowledged in the literature\(^{(65)}\). Despite these participants’ inability to be with the dying resident, they also expressed apprehension about inviting ‘strangers’ (volunteers) to carry out this role. These participants also expressed concern that if a resident deteriorates in hospital, then it is likely they will receive their end-of-life care away from ‘family’. The data revealed that the participants perceived that it was their responsibility and role to care for the resident at the end-of-life and having others involved in this care provision was difficult for them to reconcile.

**Advocacy as a key role**

Study participants expressed the desire to comply with the older person’s wishes and they perceived it to be their responsibility to uphold the residents’ requests and that this was of paramount importance. However, participants revealed that this was often difficult to achieve, especially when transfer to hospital was necessary and the preferences of the families or the doctor differed and prevailed over those expressed by the resident. It was suggested that a residents transfer to hospital was usually due to lack of a definitive diagnosis, the absence of an appropriate treatment plan or general practice workloads, ‘I’m busy… send them in…’ (registered nurse, group 2). Although, it was perceived that families largely desire that the resident actually ‘…dies in the facility where they are cared and loved’ (registered nurse, group 3), families often insisted on transfer purely for confirmation that all that is possible has been done and to ensure that the best possible care was being provided. Tension within a family and an absence of consensus about treatment plans was stated as increasing
the likelihood of a resident being transferred to hospital. There was a belief that ‘if the resident is comfortable, the family is comfortable’ (registered nurse, group 2).

Participants felt that the patients’ families often had unrealistic expectations of the role of an acute intervention and perceived that a hospital environment would provide ‘better care’ that the residential aged care facility. These participants expressed concern that an admission to hospital meant that the resident would often be in a disorientating environment, being cared for by unfamiliar staff that were unlikely to have the knowledge and competencies needed to manage their complex care needs. Hospitalisation also increased the likelihood that the resident would be subjected to a battery of invasive tests and procedures. Given these beliefs, hospitalisation was seen as not always being desirable: ‘...we resent sending residents to hospitals…’ (registered nurse, group 2) and that ‘...a hospital isn’t the optimal place for older people to be’ (registered nurse, group 3). It was suggested that families and residents needed to be provided with realistic information about the outcome of proposed treatments in order to make an informed decision about treatment options, particularly around transfer to hospital. Aged care personnel’s reluctance to referred residents to hospital also suggested a degree of ownership, which may be connected to wanting the best for residents. If this is correct, then striving for the best care for residents may make aged care providers more receptive to considering new ways of delivery care and guidance from ‘outsiders’, especially if it results in better outcomes for residents. Alternatively, ownership and knowing what’s best for residents may make it difficult to implement change and seek additional support from other health care providers.

**Communication challenges**

Similar to previously reported studies\(^{(65)}\) study participants expressed that increasingly elders admitted to residential aged care are now sicker, and have higher levels of disability and fragility. Palliative care was seen as a core component of care for these residents and participants expressed a desire to increase their palliative care competencies and confidence in order to better meet the residents’ needs. The fragility of many residents on admission had created a sense of urgency amongst participants to determine as soon as possible the resident’s desires around goals of care and advance care planning. Although the participants saw that it was their role to initiate this discussion, many felt ill prepared to facilitate this potentially difficult conversation and acknowledged that instigating this dialogue shortly after admission was less than ideal.
The care assistants (unregulated workers) described having the ability, not unlike ‘...a mother does with her sick children’ (care assistant, group 3) to detect when the resident needed to be reviewed. A sense of frustration was evident amongst care assistants as they attempted to describe the often subtle clinical changes they observed in the resident: ‘Frustrated if you cannot get proper care’ (care assistant, group 2). Despite care assistants being well positioned to observe signs of change in residents, it has been acknowledged that they are often unable to methodically document or communicate their observations[66]. In this study there was evidence that a lack of language made it difficult for care assistants to effectively convey their observations and concerns. It was suggested that the diverse skill mix in residential aged care has resulted in the professional language becoming less technical and scientific as nurses endeavoured to convey complex care concepts to care assistants. Yet these nurses also needed to have the ability to simultaneously communicate to doctors using accepted medical language: ‘You spend the bulk of your time talking to less skilled staff ...then you have difficulties finding the right words when speaking to the GP or others outside the facility’ (registered nurse, group 3). It was acknowledged that an inability to use accepted disciplinary language reflected poorly on aged care nurses and acted as a barrier to negotiating effective care for residents: ‘GP sick of getting layman’s terms’ (director of nursing, group 1). The diversity of the workforce and the inability of each tier of health care provider to effectively communicate resulted in frustration being transferred up the line: ‘Everyone wants something done, but nothing happens’ (registered nurse, group 2). These communication problems have previously been identified as a major barrier to appropriate pain management for elders in residential care[46].

The shortage of local general practitioners also caused considerable angst for these participants. Many wrestled with not wanting to add to the doctors’ workload and further alienating the doctor so that they withdrew their services all together, whilst balancing the need to act as an advocate for the resident: ‘...we (nurses and care assistants) are at the mercy of the doctor’ (registered nurse, group 3). There was a perception that many doctors only visited after-hours and often in response to an urgent request. Study findings demonstrated that many doctors found it difficult to provide assessment and care in a timely manner: ‘One GP took three weeks to come and see the resident’ (director of nursing, group 1); and another comment, ‘Sometimes it is too late’ (care assistant, group 2), referring to the time it took the doctor to visit. This concept of the doctor in aged care as ‘missing in action’ has previously been described by Miller and colleagues[67](p.720). There was also a perception that the doctors didn’t always have an interest in the needs of residents or possess adequate palliative
care skills and knowledge: ‘Many GPs are reluctant to use morphine with older people and then if they order it, they are reluctant to order a breakthrough dose’ (registered nurse, group 3). The variable quality of medical support and palliative care competencies has the potential to make the provision of evidence based palliative care in aged care difficult to achieve, particularly if the primary access to expertise is through the general practitioner\(^{(65)}\).

The data revealed significant barriers to effectively engaging a limited and over worked general practitioner workforce as collaborative partners in the provision of care to residents. There was no real sense from participants that the provision of care to residents was a multidisciplinary team effort. It also seemed that study participants largely worked in isolation from other health care providers. The wide variability in the participants’ knowledge of local resources meant that many were not aware of the availability of the local specialist palliative care team. Neither were they aware that the visiting palliative care physician could be consulted for assistance in managing residents with complex palliative care needs: ‘…we don’t have access to palliative care specialists’ (registered nurse, group 2). Avis\(^{(65)}\) and colleagues have previously reported a similar finding of isolation amongst aged care nurses in the United Kingdom.

**Battling and striving to succeed against the odds**

Participants described in detail the significant pressures they faced in providing appropriate care to residents. Data revealed that all nurses were battling and striving to succeed against the odds, particularly with regard to balancing the diverse skill mix, fiscal constraints, staff shortages and regulatory requirements in residential aged care facilities, which are concerns that have previously been detailed\(^{(65)}\). The burden of administrative work was described as being both repetitive and arduous, where the focus is on documenting normal events: ‘(You are) so busy writing about the usual that you forget about writing about what was really important’ (registered nurse, group 4). It was suggested that this documentation did not have strong validity for practice and reduced the time registered nurses had to deliver care, making them ‘afraid to ask (resident) ‘How are you?’, for fear of getting trapped ’ (registered nurse, group 4).

The issue of perceptions of status amongst aged care staff was a recurrent theme. Participants saw that a discrete set of skills was required to deal with older people with complex care needs. In spite of this, they considered acute care health professionals, doctors and very often families largely ignored their expert knowledge and skill: ‘You would like to think that they
would respect your professional judgement’ (registered nurse, group 2). Although, participants believed that they were better equipped to care for the needs of the resident than acute care staff, they were disillusioned that aged care nurses continued to have lower status, ‘We are not recognised as having a specialty’ (registered nurse, group 3) which was evident in their remuneration, community perceptions and role within the health care environment. Participants described a sense of insult that a specialist provider or a family member could very often successfully negotiate a change to care with the doctor that the nurses had been trying to effect for some time: ‘Maybe he (doctor) took more notice as she was from palliative care’ (director of nursing, group 1) and another comment: ‘The family is often greater leverage than the nurses’ calls to the GP (registered nurse, group 2).

4.4.8 Reflections on the data

The Phase One focus group data revealed that palliative care is a core activity in residential aged care and in each of the focus groups there was unanimous acknowledgment that all residents required varying degree of palliative care integrated into their care plans. Although, study participants did not specifically articulate the philosophy of the care provided as being a palliative approach, they did describe the need for residents to receive ‘acute on chronic care’ (registered nurse, group 3) and identified that ‘palliative care can be long term, not just at the end of life’ (registered nurse, group 4) and was indicated for a range of both malignant and non-malignant conditions. Of note, it was also expressed that, in many respects, residential aged care facilities were in fact de-facto hospices: ‘The whole institution is a palliative care unit (director of nursing, group 1) and ‘No one walks out of here’ (registered nurse, group 2).

Although, many residential aged care facilities appear to be functioning as slow stream hospices the importance of palliative care and related activities are largely hidden\(^{20}\). As part of a death defying society it was apparent that even within aged care it is difficult to raise the issue of mortality\(^{68}\).

These aged care nurses demonstrated a sound understanding of the needs of older people, yet desired opportunities to develop greater palliative care competencies. The entwinement of knowledge and power undeniably influence access to resources within residential aged care facilities, particularly within a context of largely unregulated workers\(^{69}\). Palliative care like other specialities has developed scientific knowledge, rules and norms, along with accepted terms and codes, which make up the language of this area of expertise\(^{70}\). In this sample aged care nurses and care assistants lacked a palliative care language set, diminishing their ability
to be truly effective advocates for residents\textsuperscript{(20)}. It would seem that the combination of an unequal skill mix, variable education levels, an older workforce, limited palliative care educational opportunities, isolation and reliance on general practitioners as their primary source of palliative care expertise serve to inhibit implementation of palliative care knowledge, skills and language within aged care\textsuperscript{(20, 65, 71)}. It became apparent that enhancing knowledge, skills and language would, likely assist residential aged care nurses to document and report a resident’s status in a more systematic way, and enhance their ability to communicate with other health care providers. In addition, families perceived lack of respect for aged care personnel’s palliative care skills may also be a potential motivator for seeking and undertaking targeted skills based education in this speciality.

Although palliative care retains a body of specialised skills and knowledge, the limited numbers of palliative care professionals and the magnitude of need dictate that collaborative, consultancy models using multi-disciplinary principles are required to optimise care in this setting. The establishing of palliative care ‘clinical champions’ within aged care facilities would enhance aged care personnel access to a resource person with the necessary skill set to guide the delivery of a palliative approach\textsuperscript{(72, 73)}. There appears to be enormous scope for the role of nurse practitioners within residential aged care facilities, particularly in relationship to the effective management of chronic and complex care, interfacing with families, facilitating advance care planning, and assisting with the management of residents’ end-of-life care needs\textsuperscript{(74)}. Yet, this issue remains fraught with political and regulatory issues\textsuperscript{(72, 74)}. The promotion and adoption of validated symptom assessment tools would assist in the delivery of evidence based palliative care to residents\textsuperscript{(75)}.

Study findings reveal that residential aged care services are already actively involved in delivering palliative care to dying residents. Further, these nurses and care assistants desire to initiate a palliative approach in advance of residents requiring end-of-life care. Palliative care services are increasingly engaging in collaborative service delivery models, yet to date residential aged care has received scant attention relative to the burden of need\textsuperscript{(76)}. Encouragingly, these nurses saw palliative care as an integral part of their work\textsuperscript{(20)}. These nurses’ and care assistants’ openly disclosed their desire to increase access to palliative care knowledge and language, promote networking with specialist colleagues and foster a multidisciplinary approach.
4.5 Propelling the action research process informed by data and enthusiasm

These focus group data provided the Critical Reference Group with ‘voices from the field’\(^{(77)}\) and a significant amount of information upon which to reflect. It was evident from the focus group data that providing palliative care in residential aged care facilities is increasingly important given the burden of chronic disease and population ageing\(^{(4, 43)}\). Despite the development of evidence based palliative approach guidelines\(^{(43)}\) the focus group data suggest that aged nurses and care assistants groups are largely unaware of this new policy direction. This finding, combined with the knowledge that significant reform in the Australian aged care sector has previously only occurred in response to legislation\(^{(78)}\), and that dissonance between clinical care and the best available evidence\(^{(79, 80)}\), all suggested that a positive policy environment alone would be insufficient to ensure the adoption of a palliative approach. A supportive organisational culture and a multifaceted intervention would be required to address these challenges in the delivery of a palliative approach to service delivery within local aged care facilities\(^{(3)}\).

These aged care nurses and care assistants are actively involved in delivering palliative care and acknowledge that this is a core element of providing clinical care. Although participants described involvement and commitment to quality palliative care, they also expressed a need for additional education and support in relation to symptom control, appropriate language descriptors and access to specialist services and resources. Providing relevant education and support will be particularly challenging as the aged care workforce is characterised by considerable diversity in educational preparation and responsibilities\(^{(6)}\). Of note, the majority of personal care in residential aged care is provided by care assistants, who are supervised by a smaller number of professional nurses\(^{(63)}\). Despite this disparity, aged care nurses and care assistants are already required to provide care to residents with progressive life limiting illnesses, managing their end-of-life care\(^{(81)}\), but the chart audit data, described earlier, suggests that there is scope to enhance the level and quality of palliative care provided to residents locally.

The focus group data also revealed that the residential aged care sector is in need of support for providing palliative care, yet there are significant personal, professional and system barriers, limiting this type of care delivery\(^{(20)}\). There was a perception that there is a need to improve links among residential aged care, primary care and specialist consultancy services to enhance communication, foster a multidisciplinary approach and improve care planning.
Table 4-7: Potential solutions to the challenges identified\(^{(20)}\)

<table>
<thead>
<tr>
<th>Issues</th>
<th>Potential Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal</td>
<td>Opportunities to develop palliative care competencies and confidence</td>
</tr>
<tr>
<td></td>
<td>Exploration of individual values and beliefs</td>
</tr>
<tr>
<td>Professional</td>
<td>Recognition of aged care nursing as a speciality</td>
</tr>
<tr>
<td></td>
<td>Integration of gerontological and palliative care knowledge, skills and language into aged care practice</td>
</tr>
<tr>
<td></td>
<td>Expanded skills set for aged care nurses</td>
</tr>
<tr>
<td></td>
<td>Enhanced status, wage parity and public perception of aged care nursing</td>
</tr>
<tr>
<td>Organisational</td>
<td>Organisational commitment to the delivery of a palliative approach to care that is reflected in policy and promotional material</td>
</tr>
<tr>
<td></td>
<td>Establishment of pre-admission clinics for residents and their families</td>
</tr>
<tr>
<td></td>
<td>Engagement of residents and families in clinical decision making processes</td>
</tr>
<tr>
<td></td>
<td>Promotion of advance care plans as a routine care planning strategy</td>
</tr>
<tr>
<td></td>
<td>Establishment of palliative care ‘clinical champions’ and institutionally based palliative care nurse specialists and nurse practitioners</td>
</tr>
<tr>
<td></td>
<td>Development of system to ensure appropriate and timely access to medical care</td>
</tr>
<tr>
<td></td>
<td>Develop process to ensure an appropriate continuum of care for residents care between health care settings</td>
</tr>
<tr>
<td></td>
<td>Creation of multidisciplinary teams to plan residents’ care</td>
</tr>
<tr>
<td></td>
<td>Multidisciplinary education, e.g. Action Learning Groups</td>
</tr>
<tr>
<td></td>
<td>Adoption of validated assessment tools and end-of-life care pathways</td>
</tr>
</tbody>
</table>
These data corroborated the needs assessment data\textsuperscript{(60)}, discussed in Chapter Two, that residents had unmet palliative care needs. Identifying these needs propelled the Critical Reference Group to identify a range of potential solutions to address the barriers to local palliative care delivery identified by aged care nurses and care assistants, as summarised in Table 4-7\textsuperscript{(20)}.

The focus group data exposed many potential areas within aged care that appeared to be primed for change. The next challenge for the Critical Reference Group was to determine which strategy was both achievable and most likely to enhance the delivery of a palliative approach in a sustainable manner and enhance the palliative care competencies of aged care nurses and care assistants. Even though the focus groups had yielded rich data about palliative care delivery in residential aged care, little was known about local aged care nurses’ and care assistants’ level of palliative care competencies or their perceived learning needs. Further, it was not known whether or not these aged care personnel had undertaken any previous palliative care education and training. Given the potential disparity that exists within the aged care workforce in terms of previous educational experience and training the Critical Reference Group suggested that nurses and care assistants were likely to have differing learning needs, particularly around symptom control and medication management. In order to support or refute this assumption and to further inform the R-PAC Project, additional data were sought.

### 4.6 Study D: Survey of views and attitudes of aged care personnel towards palliative care

As described in Chapter Three, the survey instrument ‘Tool 2.1:Palliative care providers’ views and attitudes’ (Appendix 6) was used to determine the views, attitudes and educational needs of aged care nurses and care assistants at baseline (Time 1)\textsuperscript{(82)}.

#### 4.6.1 Aim

This survey aimed to assess the views and attitudes of aged care staff towards palliative care and to identify their self-reported palliative care learning needs\textsuperscript{(83)}. 

4.6.2 Sample

The survey was administered by the researcher in a range of consultation settings that 240 aged care nurses and care assistants attended, including: project planning forums and the data feedback sessions held in local aged care facilities, which were conducted as part of the action research process.

4.6.3 Data analysis

As discussed in Chapter Three, data were entered into the Statistical Package for Social Science (SPSS) Version 14.0 to derive frequency estimates. Percentages in the tables not adding to 100 indicate missing values. Results related to ‘Views about palliative care’ have been aggregated into two categories: Group 1 (G1) with values less than 50% taken to indicate higher levels of perceived need for further support and supervision, and Group 2 (G2) with values greater than 50% taken to indicate lower levels of perceived need for further support and supervision (G2). Although these values are somewhat arbitrary they reflect significant groupings in the data. For ease of interpretation, results related to ‘Attitudes towards palliative care’ and ‘Views about death and dying’ have been reduced to three categories: agree strongly and agree have been aggregated into a category labelled ‘mostly agree’, disagree and strongly disagree have been aggregated into another category, ‘mostly disagree’, while ‘unsure/mixed’ remains unchanged. The Chi-square test was used to compare percentages, \( p<0.05 \) being used as the criterion for statistical significance. All data have been reviewed by an academic statistician.

4.6.4 Findings

A total of 222 completed surveys were returned, representing a response rate of 92.5%. The sample was composed of registered nurses \( (n=62) \), enrolled nurses \( (n=36) \), and care assistants \( (n=111) \) employed by local residential aged care facilities in Coffs Harbour\(^{83}\). Thirteen participants (6%) did not state their professional discipline; further analysis indicated that this subset was not statistically significantly different from the larger group in terms of gender or mean age. This survey sample represents half (53%, \( n=398 \)) of the total population of the local residential aged care workforce during Phase One of the R-PAC Project.
**Demographic data and professional characteristics**

Table 4-8 reports basic demographic data, professional characteristics and previous palliative care training information\(^{83}\). The majority of participants were middle aged females. Care assistants comprised half \((n=111)\) of the sample. The sample was relatively homogenous in terms of ethnicity, with only 4% \((n=9)\) identifying as being from a particular cultural or ethnic background and 2% \((n=4)\) identifying as being Aboriginal Australian. For the majority \((70\%, n=156)\) of participants their palliative care training consisted of ‘on the job’ experience, considered to be experiential learning that had taken place in the workplace, while over a tenth \((12\%, n=27)\) had no previous palliative care education and only 5 \((2\%)\) had specialist qualifications in palliative care.

**Table 4-8:** Participants’ demographic, professional details and palliative care training\(^{83}\)

<table>
<thead>
<tr>
<th>Sample</th>
<th>RN</th>
<th>EN</th>
<th>CA</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n)</td>
<td>(%)</td>
<td>(n)</td>
<td>(%)</td>
</tr>
<tr>
<td>222</td>
<td>(100)</td>
<td>62</td>
<td>(28)</td>
</tr>
<tr>
<td>Age mean ((SD)) years</td>
<td>46</td>
<td>(+9)</td>
<td>49</td>
</tr>
<tr>
<td>Female</td>
<td>195</td>
<td>(88)</td>
<td>58</td>
</tr>
<tr>
<td>Male</td>
<td>24</td>
<td>(11)</td>
<td>3</td>
</tr>
<tr>
<td>Palliative Care Training</td>
<td>None</td>
<td>27</td>
<td>(12)</td>
</tr>
<tr>
<td></td>
<td>*On the job</td>
<td>156</td>
<td>(70)</td>
</tr>
<tr>
<td></td>
<td>*Short course</td>
<td>72</td>
<td>(32)</td>
</tr>
<tr>
<td></td>
<td>*Specialist qualification</td>
<td>5</td>
<td>(2)</td>
</tr>
</tbody>
</table>

**Key:** Registered Nurse (RN), Enrolled Nurse (EN) and Care Assistant (CA);
* Total responses > 100% indicates more than one training experience
Table 4-9: Ranking of importance of issues when caring for a dying resident\(^{(83)}\)

<table>
<thead>
<tr>
<th>End-of-life care issues</th>
<th>Rank</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control of pain</td>
<td>1</td>
<td>98</td>
</tr>
<tr>
<td>The patient’s emotional needs</td>
<td>2</td>
<td>98</td>
</tr>
<tr>
<td>Communication with family</td>
<td>3</td>
<td>98</td>
</tr>
<tr>
<td>Managing depression</td>
<td>4</td>
<td>97</td>
</tr>
<tr>
<td>Communication with other palliative care staff</td>
<td>5</td>
<td>96</td>
</tr>
<tr>
<td>Ability to meet spiritual needs</td>
<td>6</td>
<td>94</td>
</tr>
<tr>
<td>Communication with (other) doctor/s</td>
<td>7</td>
<td>92</td>
</tr>
<tr>
<td>Legal concerns</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>Uncertainty about what is best care</td>
<td>9</td>
<td>68</td>
</tr>
</tbody>
</table>

**Importance of issues associated with end-of-life care**

The majority of participants ranked managing patients’ physical, emotional and spiritual needs along with communicating with family and other health care providers as being the most important issues to attend to when caring for dying patients (Refer Table 4-9\(^{(83)}\)). Legal issues and ‘uncertainty about what is best care’ rated much lower in importance. No statistically significant differences were found between nurses and care assistants for any issues.

**Views about death and dying**

Participants’ views concerning death and dying are summarised in Table 4-10\(^{(83)}\). The majority (>75%) of participants mostly disagreed with six of the 10 statements, indicating that they: do not feel that something has gone wrong when a resident dies, are comfortable caring for a dying resident, believe that there are interventions that can help a person achieve a sense of peace at the end of life, that nursing homes are appropriate places to care for dying residents and that referring a dying resident to hospice or acute care is not always indicated.

A third (32%) of participants indicated that they were unsure whether the use of strong pain medication can cause the person to stop breathing, with almost half of all care assistants being unsure about this statement. A larger percentage of care assistants compared to nurses also indicated that they were unsure about the statement that ‘feeding tubes should be used to prevent starvation at the end of life’ \((p=0.001)\).
Although the majority (78%) of the sample mostly agreed with the statement ‘that families have a right to refuse medical treatment, even if that treatment prolongs life’, care assistants were more ‘unsure’ than nurses ($p=0.02$). In terms of the remaining two statements, ‘the end of life is a time of great suffering’ and ‘I am not comfortable talking to families about death’, the participants’ views were much more widely dispersed, with large percentages indicating ‘unsure or mixed’ feelings on specific issues, and the differences between groups were not found to be statistically significant.

**Table 4-10: Views concerning death and dying**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mostly Agree</th>
<th>Unsure/Mixed</th>
<th>Mostly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The end of life is a time of great suffering</td>
<td>10</td>
<td>22</td>
<td>66</td>
</tr>
<tr>
<td>Little can be done to help someone achieve a sense of peace at the end of life</td>
<td>2</td>
<td>3</td>
<td>95</td>
</tr>
<tr>
<td>* The use of strong pain medication can cause the person to stop breathing</td>
<td>10</td>
<td>32</td>
<td>58</td>
</tr>
<tr>
<td>I am not comfortable caring for a dying patient</td>
<td>2</td>
<td>3</td>
<td>94</td>
</tr>
<tr>
<td>I am not comfortable talking to families about death</td>
<td>6</td>
<td>16</td>
<td>77</td>
</tr>
<tr>
<td>When a patient dies I feel that something went wrong</td>
<td>1</td>
<td>2</td>
<td>96</td>
</tr>
<tr>
<td>* Feeding tubes should be used to prevent starvation at the end of life</td>
<td>2</td>
<td>27</td>
<td>69</td>
</tr>
<tr>
<td>Nursing homes/hospitals are not good places to die</td>
<td>4</td>
<td>12</td>
<td>83</td>
</tr>
<tr>
<td>* Families have the right to refuse a medical treatment, even if that treatment prolongs life</td>
<td>77</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>Dying patients should be referred to a hospice or acute care</td>
<td>3</td>
<td>15</td>
<td>80</td>
</tr>
</tbody>
</table>

**Key:** * Statistically significant difference between views of RN, EN and CA (See p.125)
Attitudes towards palliative care

Table 4-11 summarises participants’ attitudes towards palliative care\(^{(83)}\). The majority (>75%) of participants ‘mostly agreed’ with 7 of the 15 statements, suggesting that the participants believed that: *residents should be kept pain free and that analgesia should be given as needed to terminally ill residents and used for conditions other than cancer; residents should have the right to determine their own degree of medical and psychosocial intervention; palliative care should be the standard treatment for patients with a terminal illness; and spiritual care should include counselling the terminally ill patient.* The majority (>75%) also ‘mostly disagreed’ with four of the remaining statements, indicating that these participants were comfortable talking about death and dying and do not believe that discussions about end-of-life care should be deferred until no further treatment is available, and that residents should not experience discomfort prior to receiving the next dose of analgesia. However, care assistants were more likely than nurses (70% versus 34%, \(p=0.013\)) to disagree with the statement that ‘pain at the end of life is an inevitable part of the dying process’.

The responses for the remaining statements tended to be more varied, with a larger number of participants tending to ‘neither agree nor disagree’. Ambivalence was observed in group attitudes towards talking to terminally ill patients and identifying the person who was the most appropriate to make end-of-life decisions. Interestingly, a third of participants ‘neither agree nor disagree’ with the statement that the patient’s primary care provider was the most appropriate person to make end-of-life decisions, yet the majority of registered nurses compared to the care assistants (65% versus 41% , \(p=0.026\)) ‘mostly disagreed’ with this statement.

Degree of confidence with patient, family interactions and patient management

As detailed in Table 4-12\(^{(83)}\), the majority of participants indicated that they were ‘basically independent’ to manage 8 of the 12 patient/family interactions and patient management situations and ‘basically dependent’ in the remaining four situations. Statistically significant differences between the various disciplines’ abilities to manage these interactions were found for all of these encounters.
### Table 4-11: Attitudes toward palliative care

<table>
<thead>
<tr>
<th><strong>Mostly Agree (%)</strong></th>
<th><strong>Neither Agree nor Disagree (%)</strong></th>
<th><strong>Mostly Disagree (%)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>16</td>
<td>80</td>
</tr>
<tr>
<td>Pain at the end of life is an inevitable part of the dying process</td>
<td></td>
<td></td>
</tr>
<tr>
<td>93</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Pain medication should be given as needed to terminally ill patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>79</td>
<td>17</td>
<td>4</td>
</tr>
<tr>
<td>Spiritual care should include counselling the terminally ill patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>16</td>
<td>80</td>
</tr>
<tr>
<td>I do not like talking about death and dying with patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>83</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>92</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Patients should have the right to determine their own degree of medical intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>74</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>14</td>
<td>75</td>
</tr>
<tr>
<td>Opening discussions of end-of-life care should be deferred until there is no further effective curative treatment available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>19</td>
<td>73</td>
</tr>
<tr>
<td>Estimation of pain by an MD or RN is a more valid measure of pain than patient self-report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>86</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition such as cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>89</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Patients have the right to determine their own degree of psychosocial intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>32</td>
<td>49</td>
</tr>
<tr>
<td>*The most appropriate person to make end-of-life decisions is the patient’s primary care provider</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>92</td>
</tr>
<tr>
<td>A patient should experience discomfort prior to receiving the next dose of pain medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>89</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Patients should be maintained in a pain-free state</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>34</td>
<td>59</td>
</tr>
<tr>
<td>As a rule, terminally ill patients prefer not to talk about death and dying</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Key:** * Statistically significant difference between attitudes of RN, EN and CA (see p. 127)
### Table 4-12: Level of independence in patient/family interactions and patient management

| Table 4-12: Level of independence in patient/family interactions and patient management
| --- |
| **Sample** | Sample 
(n= 222) | RN 
(n= 62) | EN 
(n= 36) | CA 
(n= 111) |
| | G1 (%) | G2 (%) | G1 (%) | G2 (%) | G1 (%) | G2 (%) |
| *Answering patients questions about the dying process* | 48 | 52 | 29 | 70 | 44 | 56 | 60 | 40 |
| *Supporting the family when they become upset* | 22 | 78 | 10 | 90 | 20 | 80 | 33 | 67 |
| *Informing people of the support services available* | 60 | 38 | 48 | 50 | 53 | 45 | 70 | 29 |
| *Discussing different environmental options* | 51 | 47 | 29 | 71 | 47 | 50 | 68 | 31 |
| *Discussing patient’s wishes after their death* | 41 | 58 | 15 | 85 | 48 | 50 | 57 | 42 |
| *Answering queries about the effects of certain medications* | 69 | 30 | 36 | 64 | 72 | 22 | 87 | 13 |
| *Reacting and coping with pain* | 27 | 72 | 16 | 84 | 26 | 73 | 35 | 65 |
| *Reacting and coping with terminal delirium* | 41 | 58 | 42 | 58 | 25 | 69 | 49 | 51 |
| *Reacting and coping with terminal dyspnoea* | 40 | 58 | 32 | 66 | 25 | 70 | 50 | 50 |
| *Reacting and coping with nausea and vomiting* | 21 | 77 | 16 | 84 | 11 | 88 | 29 | 69 |
| *Reacting and coping with constipation* | 19 | 81 | 7 | 93 | 6 | 94 | 30 | 70 |
| *Reacting and coping with limited patient decision making capacity* | 33 | 66 | 23 | 76 | 28 | 72 | 42 | 58 |

**Key:** Basically dependent (G1) and basically independent (G2), Registered Nurse (RN), Enrolled Nurse (EN) Care Assistant (CA)

* Statistically significant difference between views of RN, EN and CA (See p. 127)

### Palliative care education needs

Participants were asked to indicate whether or not they required further education on nine specific palliative care topics. Responses are summarised in Figure 4-8 and indicate that there were different education needs perceived for registered nurses, enrolled nurses and care
The majority of care assistants and enrolled nurses requested more pain assessment and management education, while a larger percentage of registered nurses desired further education to deal with nausea/vomiting and hydration related issues, including the use of intravenous hydration and/or non-oral feeding in end-of-life care. End-of-life communication skills including giving bad news, talking with family, discussing prognosis and various treatment options were rated highly for all groups. Statistically significant differences were found between registered nurse, enrolled nurse and care assistant subgroups’ need for further education related to the palliative management of pain, nausea/vomiting and hydration.

![Figure 4-8: Perceived palliative care educational needs of aged care personnel](image)

### 4.6.5 Discussion

The profile of the participants in this study is typical of the Australian residential aged care workforce in terms of gender, age and educational preparation. However it is atypical in terms of the smaller numbers of participants identifying as coming from a culturally diverse or indigenous background and there is more workforce stability than in metropolitan areas. This study confirms earlier observations that few aged care nurses have specialist palliative
care qualifications\textsuperscript{(38, 76, 85)}). Accessibility to suitable palliative care courses for aged care nurses and particularly care assistants\textsuperscript{(86)}, along with availability and affordability, may also have contributed to the low levels of specialist qualifications amongst these rural participants. As a consequence, the most likely form of palliative care education was ‘on the job training’. In Australia, at the time of this study, minimal palliative care education had been undertaken by aged care personnel\textsuperscript{(87)} and less than half of all specialist palliative care teams had conducted education in the residential aged care setting\textsuperscript{(76)}. From these data reported above, it appears that targeted palliative care education is required because a lack of palliative care training has previously been identified as being a major obstacle to the delivery of palliative care in the aged care setting\textsuperscript{(85, 86, 88)}. This finding is particularly important as appropriate education and support are required to ensure that nurses and care assistants caring for dying people have the necessary palliative care competencies and do not merely adopt the behaviour of those around them\textsuperscript{(89)}. In an environment, where little if any palliative care education has previously been provided, peer modelling is particularly relevant, as the usual treatment and care provided within the aged care facility may not always have been based on best available evidence.

Not surprisingly, this study found differences in nurses’ and care assistants’ palliative care confidence and ability to manage a range of patient and family interactions that were implicitly linked to professional roles, prior training and educational preparation. The wide variability in aged care personnel’s responsibilities and palliative care competencies suggests that a team approach to care planning and delivery is required to compensate for the diverse skill mix in the aged care workforce. Residential aged care has previously been described as an isolated health care environment wherein nurses have limited networking opportunities and a lack of contact with clinical experts, and experience difficulties accessing specialist services\textsuperscript{(65)}. This isolation is reflected in the low levels of awareness of existing support services observed in this study. Further, it is known that the local specialist team has had limited input into the provision of residents’ care\textsuperscript{(20)} and aged care education\textsuperscript{(76)}.

In this study, care assistants who as a group have less formal educational preparation than nurses, indicated greater uncertainty about the use of artificial hydration, the rights of families to refuse treatment, whether the residents’ general practitioner was the most appropriate person to make end-of-life decisions and uncertainty about what is best care. Care assistants didn’t accept that pain at the end-of-life was inevitable suggesting that they were committed to ensuring that dying resident’s remained pain free. The challenge however, for these
unskilled workers is securing the same level of commitment from nurses who administer the bulk of analgesics. Whereas, registered nurses, who on the whole have more formal education than care assistants, demonstrated a greater understanding of the complexity of clinical decision making at the end-of-life and appreciated the need to engage others in this process.

The under-treatment of residents’ chronic and acute pain\(^{(90)}\) and the barriers and deficits preventing effective pain management in residential aged care are well documented\(^{(7, 45-47)}\). This study confirms findings from previous studies that nurses and care assistants identify the need to manage resident’s pain more effectively\(^{(91)}\), yet lack knowledge about the pharmacology of certain palliative care medications\(^{(45)}\). In addition, this study identified that nurses and care assistants have misconceptions about opiate usage, including when it should be introduced, and hold ambivalent views towards pain management, particularly at the end-of-life. Although education is necessary to increase pain management knowledge, it is inferred from these finding that there is also a need to encourage aged care nurses and care assistants to engage in reflective practice so they become aware and comfortable with their own views about pain and analgesic use in order to effect positive resident outcomes\(^{(92, 93)}\). Previous research has raised questions about the adequacy of in-service pain education conducted by aged care staff and suggested that collaboration with external experts may be required to optimise the impact of the learning experience\(^{(94)}\). The need to involve external experts is an important consideration when developing targeted aged care education programs.

This study found that nurses and care assistants have commitment and compassion for dying residents and their families; these positive attitudes are likely to be reflected in the care provided\(^{(83, 87)}\). The majority of nurses and care assistants believed that aged care facilities are appropriate places for dying residents and are reluctant to transfer residents to the acute care setting, reflecting their commitment to manage residents’ end-of-life care within the facility.

### 4.7 Moving forward in the action research process

A range of factors converged during the course of the R-PAC Project to drive clinical change including: (1) funding of a three year local rural palliative care project aimed at strengthening palliative care partnerships; (2) identifying the unmet palliative care needs of older people in residential aged care; (3) the releasing of evidence based palliative approach guidelines and
(4) harnessing enthusiastic support from aged care personnel to work collaboratively with the researcher to promote the delivery of a palliative approach.

The chart audit confirmed that older people dying in local residential aged care facilities have unmet palliative care symptom management and care planning needs. The focus groups and survey conducted during Phase One reveal that Coffs Harbour aged care nurses and care assistants were committed and compassionate about delivering palliative care to residents and expressed a need to acquire palliative care competencies and confidence\(^{20}\). The heterogeneity of roles, responsibilities and levels of education suggested that any educational initiatives should be tailored to meet the discrete learning needs of aged care nurses and care assistants. In addition, aged care providers’ lack of awareness of available local specialist palliative care services was seen as a barrier to accessing specialist advice, which is often required for the managing residents with complex palliative care needs. As behaviour change rarely occurs solely through the acquisition of new knowledge there is also a need to provide aged care personnel with opportunities to explore their own values and attitudes towards a range of ethical, legal and moral issues related to end-of-life care\(^{95}\). The increasing role of residential aged care facilities in dealing with death and dying makes exploring of these issues of critical importance\(^{20}\).

Based on these data the Critical Reference Group identified that a multifaceted intervention was required, including a tailored palliative care learning and development strategy for aged care nurses and care assistants. The following chapter details the development of the multifaceted intervention to enhance palliative care competencies of residential aged care nurses and care assistants so they are better equipped and confident to deliver a palliative approach to older people in long-term care.
4.8 Reference list


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52. Kitzinger, J. (1994). The methodology of focus groups: the importance of interaction between research participants. *Sociology of Health and Illness, 16*(1), 103-21.


77. van Eyk, H., & Baum, F. (2003). Evaluating health system change - Using focus groups and a developing discussion paper to compile the "voices from the field". *Qualitative Health Research, 13*(2), 281-6.


CHAPTER FOUR


Chapter 5.

Partners in Developing a
Strategy to Facilitate a
Palliative Approach in
Residential Aged Care
‘Alone we can do so little; together we can do so much’

Helen Keller

5.1 Introduction

As detailed in Chapter Four, the diagnostic phase of the action research process confirmed that there was scope to enhance the delivery of palliative care to better address residents’ and families’ care needs. As discovered in the diagnostic phase, aged care nurses and care assistants had a need for: acquiring greater palliative care competencies and confidence; obtaining the specialist language of palliative care; and improving their palliative care networks\(^{(1)}\). An action research framework was adopted to ensure that key stakeholders were engaged in a change process that offered the greatest potential to generate genuine and sustained improvement in practice. This approach also enabled participants to acquire a greater understanding of the R-PAC Project’s impact and to promote sustainability.

This chapter will detail how the PRECEDE framework\(^{(2)}\) was used as an organisational framework for integrating the baseline data and designing a targeted multifaceted intervention. The needs assessment data combined with the findings from the literature guided the Critical Reference Group’s development of an intervention to address the gaps in palliative care service delivery and aged care nurses and care assistants professional knowledge and competencies.

5.2 Applying the PRECEDE framework

Applying the needs assessment to the PRECEDE framework, as part of the Educational Diagnosis enabled the Critical Reference Group to assess all the components identified during the needs assessment as either limiting or enabling the delivery of a palliative approach in local aged care facilities. These barriers and facilitators were further classified as being predisposing, reinforcing or enabling factors. The next step for the Critical Reference Group was to prioritise and identify the factors considered most important and amenable to positive behaviour change. A summary of the outcome of this process is detailed in Tables 5-1 to 5-3.
5.2.1 Predisposing factors

The knowledge, attitudes, beliefs, perceptions and values of health care providers, residents and their families were assessed by the Critical Reference Group. This process revealed a diverse range of predisposing factors acting to either motivate or inhibit the delivery of a palliative approach in local residential aged care facilities (Table 5-1). Applying the PRECEDE ranking formula and prioritising these factors in terms of their importance and potential to respond positively to the intervention\(^2\) assisted the Critical Reference Group to identify the predisposing factors warranting further attention. The predisposing factors ranked most highly by the Critical Reference Group were:

1. Aged care nurses’ and care assistants’ need for:
   - increased awareness of a palliative approach;
   - enhanced palliative care competencies and confidence; and
   - increased awareness of local palliative care resources;

2. Aged care nurses’ and general practitioners’ awareness of the appropriateness of seeking specialist palliative care input for residents with complex palliative care needs;

3. The need to increase availability and access to general practitioners who were prepared to review residents in the aged care setting; and

4. The need to increase residents’ and families’ awareness of the meaning of a palliative approach to care and increase their involvement in care planning.
### Table 5-1: Predisposing factors

<table>
<thead>
<tr>
<th>Predisposing factors</th>
<th>Importance</th>
<th>Changeability</th>
<th>Total</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses’ and care assistants’ limited awareness of a palliative approach</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Nurses’ and care assistants’ limited awareness of local specialist palliative care team</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Nurses’ and care assistants’ limited awareness of palliative care resources</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Nurses’ and care assistants’ palliative care knowledge and skills</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Nurses’ and care assistants’ limited understanding of the use of palliative care drugs</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Residents with complex symptom control problems not being referred to the palliative care team for assessment</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Nurses and care assistants working in relative isolation</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>GP availability &amp; preparedness to visit residents</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Residents and families awareness of a palliative approach</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Residents’ and families’ determining of goals of care</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Residents’ and families’ acceptance of a palliative approach to care</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Residents’ and families’ willingness to complete an advance care plan</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Residents’ and families’ acceptance of death</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>GPs’ awareness of a palliative approach</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>GPs’ palliative care knowledge and skills</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>No defined resident to carer/nurse ratios</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Nurses being overburdened with documentation</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Bulk of personal care being provided by care assistants (unregulated workers).</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

Key: Low =1, Medium = 2, High = 3
5.2.2 Reinforcing factors

Reinforcing factors serve to strengthen the motivation for behaviours\(^{(2)}\). In the residential aged care setting, residents, family members, other health care providers, peers and educators all play a role in the reinforcement of both positive and negative behaviours through the use of rewards, feedback and punishments\(^{(2)}\). The reinforcing factors considered most important and amenable to change by the Critical Reference Group in the delivery of a palliative approach (Table 5-2) included the need to:

1. Increase aged care nurses’ and care assistants’ awareness of the specialist palliative care referral process;
2. Develop appropriate systems for general practitioners to be engaged in care planning, including end-of-life care planning;
3. Provide residents and families with information to inform their decisions about the adoption of a palliative approach; and
4. Increase the visibility and 'normalisation' of a palliative approach in residential aged care facilities.

5.2.3 Enabling factors

Enabling factors are a composition of characteristics of the environment (public policy and relevant laws) that facilitate action and the skills and resources required to achieve a desired behaviour\(^{(2)}\). Factors such as accessibility, availability and skills were identified as impacting on aged care nurses’ and care assistants’ ability to deliver a palliative approach in the aged care sectors (Table 5-3).
Table 5-2: Reinforcing factors

<table>
<thead>
<tr>
<th>Reinforcing factors</th>
<th>Importance</th>
<th>Changeability</th>
<th>Total</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged care nurses’ and care assistants’ limited awareness of the referral process to access the local specialist palliative care team</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>No systems in place to encourage GPs to adequately plan and manage resident’s end-of-life care</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Families not being provided with an opportunity to consider a palliative approach to care</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Provision of information to residents and families about a palliative approach to care (i.e. pamphlets, posters, information sessions and discussions during the admission process)</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Public display of information about palliative care and local resources within the facility</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Families perceiving that the resident will get better care in hospital</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Lack of family consensus regarding the goals of care resulting in the resident being transferred to hospital for assessment and treatment</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Difficulty accessing a GP in a timely manner to assess a resident with a change in physical status.</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>GPs requesting that a change in residents physical status requires assessment at local acute hospital</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

Key: Low =1, Medium = 2, High = 3
### Table 5-3: Enabling factors

<table>
<thead>
<tr>
<th>Reinforcing factors</th>
<th>Importance</th>
<th>Changeability</th>
<th>Total</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged care nurses and care assistants being able to work as a team</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Care assistants being empowered to report their clinical findings/observations to nurses</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Aged care nurses and care assistants being able to communicate clinical assessment findings to external health care providers</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Aged care nurses and care assistants being able to effectively advocate to the resident in accordance with their wishes</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Aged care nurses and care assistants being able to communicate in the language of palliative care</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Timely access to appropriate equipment (e.g. pressure relieving mattresses and syringe drivers)</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Nurse initiated referral to specialist palliative care team</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Aged care nurses and care assistants who are able to demonstrated palliative care competencies</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Palliative approach education provided locally</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Timely access to appropriate and affordable medications</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Promotion of a palliative approach to care by aged care management</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Endorsement and adoption of a palliative approach to care by aged care management</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>24 hour access to a Registered Nurse</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

Key: Low =1, Medium = 2, High = 3
The enabling factors considered most important and amenable to change by the Critical Reference Group in the delivery of a palliative approach include aged care providers’ capacity to:

1. Communicate clinical findings to external health care providers;
2. Effectively advocate on behalf of the residents;
3. Utilise a common palliative care language, internally within the facility and externally to other providers;
4. Arrange timely access to palliative care equipment;
5. Refer the resident to the specialist palliative care team;
6. Engender opportunities for aged care nurses and care assistants to acquire greater palliative care competencies and confidence; and
7. Access education regarding the palliative approach locally.

5.3 Using Action Research to address the need

During Phase Four (Educational Diagnosis) of the PRECEDE framework it was recognised that a complex array of factors were acting to limit residents’ access to a palliative approach, including: i) the lower ratio of registered nurses as a proportion of the total aged care workforce; ii) nurses’ and care assistants’ perception of their limited palliative care knowledge, skills and confidence; iii) under utilisation of the specialist palliative care team; iv) difficulty accessing timely and appropriate medical intervention, specialist support, medications and equipment; and iv) residents’ and families’ limited awareness and understanding of a palliative approach. These data combined with findings from the literature and feedback from the key stakeholders shaped the intervention objectives developed by the Critical Reference Group (Table 5-4).
### Table 5-4: R-PAC Project’s intervention objectives

<table>
<thead>
<tr>
<th>R-PAC Project’s intervention objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>By December 2005, 100% of aged care facilities in Coffs Harbour will have a minimum of one registered nurse per 50 beds with demonstrated palliative care competencies.</td>
</tr>
<tr>
<td>By December 2006, 50% of care assistants employed in Coffs Harbour local aged care facilities will have completed appropriate palliative care education.</td>
</tr>
<tr>
<td>By December 2006, 80% of aged care facilities in Coffs Harbour will have endorsed the adoption of the Commonwealth Governments ‘Guidelines for a Palliative Approach Guidelines in Residential Aged care.’</td>
</tr>
<tr>
<td>By December 2006, 90% of all residents will receive their end-of-life care within the aged care facility.</td>
</tr>
</tbody>
</table>

The priority outcomes set by the Critical Reference Group determined that a multifaceted intervention was needed to prepare aged care personnel for the changes required to enable them to deliver a palliative approach. This intervention needed to include strategies to: i) increase their palliative care competencies; ii) allow exploration of values and beliefs related to the care and management of the dying; iii) enhance communication skills, particularly regarding initiating and facilitating discussions relating to goals of care, advance care planning and decision making at the end-of-life; iv) facilitate greater utilisation of the specialist palliative care services to assist with the management of residents with complex care needs; and iv) engender greater confidence to engage residents’ and families’ in conversations about a palliative approach and the implications for care delivery.

Given the diversity of the aged care workplace, the Critical Reference Group considered that addressing the unique learning needs of registered nurses, care assistants and general practitioners would require the development of tailored learning and development strategies specific to educational levels and scope of practice. An intervention to address the needs of general practitioners was undertaken independently of the R-PAC Project described in this Thesis. The Critical Reference Group acknowledged that the needs of residents and families required an approach which would be explored in greater depth following the implementation of the learning and development intervention for aged care providers.
5.4 Drawing on the palliative and aged care education literature

Expert consultation and an integrative literature review\(^{(1)}\) was undertaken to guide the development of a learning and development intervention appropriate to the needs of aged care nurses and care assistants in mid 2004. CINAHL, PubMed and MEDLINE electronic databases were searched to identify relevant literature published in the English language from 1990 to 30 June 2004 to inform intervention development. Keywords used in this search included: ‘education*’, ‘learning*’, ‘adult education’, ‘palliative care’, and ‘aged care’. Reference lists of retrieved articles were searched for additional literature. Relevant journals held locally were hand searched for pertinent articles and the Internet was searched using the Google search engine for related organisations or electronic documents using the keywords listed previously. In mid 2004, when this literature review was undertaken there was only a small body of evidence relating to the palliative care needs of older people in residential aged care. It is this literature which informed the development of the intervention.

5.4.1 Palliative care for people with non-malignant disease

Both internationally and nationally, specialist palliative care services have evolved rapidly over the past 30 years to meet the needs of people with advanced malignancy\(^{(3)}\). The notion that specialist palliative care was indicated for people with non-malignant disease was first mooted in the 1980s, but it took another decade for this debate to gain momentum\(^{(4)}\). A systematic review of palliative care studies undertaken during the 1990s\(^{(5)}\) detected high symptom burden for people dying from non-malignant disease. A UK nursing study found a perception amongst nurses that patients with non-malignant disease were less likely to experience pain and had less urgent palliative care needs than those with a malignancy\(^{(6)}\). Another study found that physicians were reluctant to refer their patients with non-malignant disease to specialist palliative care services because of concerns about how the patient and family would perceive this action\(^{(7)}\). This finding suggests a general reluctance amongst these physicians to discuss the implications of a palliative care referral and end-of-life care with patients and their families\(^{(7)}\). Of note, few geriatricians surveyed in this study considered conditions such as stroke and dementia warranted specialist palliative care input\(^{(7)}\). Palliative care is now increasingly being viewed as being indicated for a range of people with chronic progressive non-malignant diseases\(^{(8-12)}\).
Field and Addington-Hall\(^3\) identified five potential barriers that prevent specialist palliative care services from being extended to non-malignant populations, including: i) the perception that specialist palliative care providers lack the skills required to care for people with a non-malignant disease; ii) that health care providers have difficulty identifying who should receive palliative care services; iii) an inadequate understanding of the role and acceptance of palliative care outside of malignant populations; iv) the resource implications of extending specialist palliative care services; and v) that there is a vested interest in some sectors of health in maintaining the status quo\(^3\). In the new millennium, many of these barriers persist despite the emerging trend towards providing a population based approach to palliative care delivery.

5.4.2 Residential aged care culture

In Australia, aged care is constructed as ‘industry’ rather than ‘service’ and this shapes the nature of care provided. This complex care environment has evolved out of an amalgam of health, welfare and private enterprise that is now heavily legislated and regulated\(^{13-15}\). Major changes have been occurring in this industry since the mid-1980s, commencing with the Aged Care Reform Strategies and the subsequent 1997 Aged Care Act\(^{14}\). This current Act defines ‘care’ in terms of services or accommodation\(^{15}\) and emphasises ‘ageing in place’. Consequently, older people are remaining in the community for longer periods of time and are now rarely admitted to aged care for short term rehabilitation\(^{16}\). This legislation also marked the transition from a welfare system towards a user pays system of aged care with an economic emphasis to minimise labour costs and maximise profits\(^{15}\). Of significance, the legislative need for aged care facilities to have 24 hour care provided by registered nurse has been repealed, which has significantly altered the resident-nurse ratio in the aged care sector\(^{14, 15}\). Increasingly older people admitted to residential aged care are cared for by unregulated workers\(^{16-18}\), while registered nurses are relegated to management duties\(^{15, 19}\).

This situation is compounded by a nursing shortage which has forced many providers to allocate more duties to care assistants, many of whom have no formal training\(^{20, 21}\). Nay et al. have suggested that the majority of nurses working in aged care hadn’t upgraded their qualifications since registration, with many viewing their employment as an additional source of income as opposed to it being a serious career choice\(^{19}\). The devalued image of aged care, poor remuneration and status, combined with limited gerontological educational opportunities and aged care career pathways are further deterrents for choosing to establish a career in aged...
Yet, without an adequate supply of caring, motivated and suitable trained personnel it is almost impossible to achieve quality health care in any setting\(^{(24)}\). Stringent government regulatory requirements, aged care funding arrangements, the poor image of aged care\(^{(19)}\) and recent adverse publicity have all contributed to a sense of powerlessness among aged care nurses and care assistants\(^{(15,25)}\).

The aged care legislative reform\(^{(14)}\), whilst promoting a more social model of care has failed to address older peoples’ need for health care delivered by professionals, especially given older peoples complex care requirements\(^{(15)}\). The bitter irony is that this legislation was enacted at a time when few older people were choosing admission to aged care for social reasons\(^{(26)}\). The main reasons people are now admitted to residential aged care is because: they require ongoing skilled nursing care, require terminal care, lack a primary care giver, or their care needs exceed community resources\(^{(16,27)}\). As a result, aged care facilities now lie at the interface between continuing care for older people and palliative care\(^{(4)}\). The emphasis of aged care work is changing as aged care facilities increasingly functioning as slow stream hospices as opposed to social care and rehabilitation centres\(^{(1,28)}\).

Despite this change, the culture of care in aged care continues to be grounded in a model of rehabilitation and health maintenance, which effectively acts to limit end-of-life care issues discussions\(^{(1,29,30)}\). The aged care standards reinforce this reality, focussing on ensuring that the highest level of resident functioning be maintained at all times. Consequently, signs of weight loss and dehydration are interpreted as evidence of poor quality care. While these are important signs of inadequate care for the bulk of the aged care population, they are also markers of inevitable deterioration at the end-of-life\(^{(27)}\). The challenge for aged care providers is to be able to accurately identify and assess the underlying cause of these clinical changes and to act accordingly. Otherwise, the use of weight loss and dehydration as quality indicators creates goals that are at odds with quality end-of-life care and leaves little opportunity for exploring resident’s preferences and acceptance of decline as part of the deterioration process\(^{(27)}\). Further, the lack of access to professional health care and equipment within the Commonwealth funded Australian aged care setting means that older people end up being inappropriately transferred to the State funded acute care setting causing a costly rebound affect\(^{(15,26)}\), which is particularly relevant to older people requiring palliative care\(^{(1)}\).
5.4.3 Palliative care in residential aged care

In the developed world there is an increasing emphasis on healthy and productive ageing (31). Notwithstanding the attention placed on prevention, rehabilitation and healthy ageing, death continues to occur in the aged care sector (32). Abbey et al. suggest that this increased focus on healthy ageing has made it difficult to draw attention to policy and practice changes required to enhance end-of-life care for older people in permanent care (33). This is reflected in studies which have identified numerous barriers to the delivery of palliative care to older people, with untreated pain being a very common problem (34-38), along with poor communication between providers (27) and limited use of advance care planning (30, 39).

A study by Teno and colleagues found that over 40% of older people in USA nursing homes who had pain on initial assessment still were experiencing severe pain 60-180 days later (38). An Australian study found 22% of residents who stated they had pain were not given any analgesic, while 16% did not have an analgesic order (35). Older residents with non-malignant diseases and those with cognitive impairment are most at risk of inadequate assessment and management of pain (40). Miller and co-workers found that residents enrolled with a specialist palliative care service have better pain management compared to those who were not enrolled (37).

In Australia, two studies conducted in the mid 1990s attempted to describe palliative care in residential aged care (41, 42). Both of these studies were undertaken prior to the amalgamation of nursing homes and hostels into one funding system in 1997 (14), which introduced for the first time a standard for palliative care provision (39). The initial study found that aged care providers were willing to provide end-of-life care but required additional: medical support, funding, pain assessment tools, staff training and increased liaison with specialist palliative care services (42). The second study found a lack of adequate funding and education, debriefing for staff and inadequate bereavement care arrangements acted to limit optimal palliative care delivery in residential aged care (41). These findings are similar to a large UK study which also examined the care of residents in nursing homes (43). This study concluded that adequate staffing, education for all staff, appropriate equipment, good general practitioner support and greater involvement with specialist palliative care teams was required to facilitate better palliative care provision (43).
Sander and colleagues have suggested that residential aged care facilities could develop a palliative approach to care by: better managing residents’ symptoms; developing an ethos of care that acknowledges that death frequently occurs in this setting; encouraging staff to better attend to residents’ spiritual needs; offering caring and appropriate information to residents and their families; and attending to the needs of residents’ families and friends, as well as the needs of other staff\(^{(44)}\). This approach is particularly relevant as palliative care may be of equal, if not of more value to the family than to the person dying\(^{(45)}\). A study conducted by Wilson et al. found families perceived that aged care nurses played a key role in creating a supportive and caring atmosphere when the resident’s condition was deteriorating\(^{(46)}\). The nursing practices that families identified as being supportive included aged care nurses and carers taking the time to inquire after their well-being, asking if they required anything, arranging spiritual support for the resident, listening to the families’ concerns and explaining to them about advance care directives\(^{(46)}\).

Avis and colleagues found that costs associated with extra staff and the need for additional training and equipment, combined with the increased acuity of residents being admitted later in their illness trajectory, meeting their social and symptom control needs, and liaising with other services made the provision of palliative care in the UK aged care setting difficult\(^{(47)}\). Directors of nursing expressed concern about the quality of palliative care that could be provided by existing aged care staff, particularly as the bulk of care is provided by untrained carers\(^{(47)}\). Opportunities for palliative care training and increased liaison with the specialist palliative care team were recommended\(^{(47)}\). A USA focus group study identified aged care nurses’ and care assistants’ main concerns as being symptom management, communication, role delineation, time constraints, self-care needs and emotional attachment to the residents\(^{(48)}\).

### 5.5 Palliative care education as a strategy to improve care

Education has been identified as a means by which the delivery of best evidence based palliative care can be promoted in residential aged care settings\(^{(4, 25, 43, 47, 49, 50)}\). Despite the widespread endorsing of the need for education, concerns have been raised about the applicability of transferring a specialist palliative care model, derived from a cancer care model, to the aged care setting\(^{(4)}\). This issue suggests that there is both a need to explore older people’s understandings of their own deaths and to ensure that any palliative care education values and builds upon aged care providers’ existing gerontological competencies\(^{(1, 4)}\).
At the commencement of the R-PAC Project, the literature revealed that the majority of education programs implemented to enhance palliative care delivery in the aged care sector (43, 47, 51-53) tended to adopt one of four approaches (47): i) specialist support and ad hoc education; ii) tailored palliative care education programs; iii) link nurse programs; or iv) a combination of specialist support and tailored education (47).

5.5.1 Specialist support and ad hoc education

A USA project utilised a pain and palliative care consultative service in nursing homes (53). This project enabled specialist nurses to model appropriate assessment and communication and management of dying residents to aged care providers (53). A collaborative study conducted at six community nursing homes owned by the same organisation in the USA established weekly consultations with a palliative care nurse specialist and provided palliative care education for all levels of aged care staff (30, 53). This intervention was provided to four of the homes with the two remaining homes acting as controls (30, 53). Staff were provided with skills and appropriate tools with the aim that key issues of pain, emotional support and advance care planning became a routine element of residents’ care (53). An evaluation of the intervention revealed that staff were more comfortable with talking about dying with residents and their families (53). However, limited resources constrained the provision of psychological support to residents and their families and influenced staff turnover. Turnover of senior aged care personnel, such as the director of nursing, impacted adversely on the effectiveness of the intervention, which highlights the importance of leadership in the change process (30, 53). The intervention was most effective in organisations with a stable and committed aged care workforce (30).

5.5.2 Tailored palliative care education programs

A UK study focused on teaching palliative care principles to nursing home care assistants (54). Although these participants perceived that the education sessions were helpful, the degree to which learning impacted on palliative care delivery in the nursing home was not evaluated (54). Another two year palliative care education program was provided to 341 aged care staff employed at 54 nursing homes in the UK during 1996-98 (51). This program was based on five key principles: i) a focus on quality of life, including good symptom control; ii) adopting a whole person approach to care; iii) care which encompasses the residents and the people who matter to them; iv) promoting respect and choice; and v) engaging in open and sensitive
CHAPTER FIVE

5.5.3 Link Nurse Programs

A link nurse has been defined as:

A nurse who has developed an interest, received training and pursues ongoing education in the philosophies, principles and practices of palliative care. While not expected to be an expert in palliative care, the ‘link nurse’ will understand the knowledge, skills and attitudes which belong to palliative care and will promote and facilitate the care of the terminally ill resident in the aged care facility to ensure they receive appropriate palliative care (25) (p.v).

The link nurse program is reported to have been used in the aged care settings in both the UK and Australia to improve palliative care delivery and communication between residential aged care staff and the specialist palliative care service (25). The effectiveness and sustainability of the link nurse program has yet to be evaluated.

5.5.4 Summary

Overall, the lack of pre-intervention data limited the degree to which any changes could be attributed to the education intervention or other factors in many of these studies (52). However, the findings suggest that any education initiatives need to be targeted to the specific learning needs of aged care personnel and, given the high turnover that occurs in this sector, these initiatives need to be ongoing within the organisation (27). A number of key elements have been identified as being critical to success for introducing palliative care into the aged care

communication (55). Nurses (n=151) attended a 12-day course for one day per week with the opportunity to complete a written assignment leading to academic accreditation at Level 2 (51). Care assistants (n=115) attended a seven day course and ancillary staff (n=75) took part in a one-day palliative care course (51). Evaluation of the impact of this education program on residents, people involved in the project and participating and non-participating nursing homes using case study and survey methods was undertaken in 1997-99. The evaluation revealed that the education program had some impact on residents and their families and work practices, but the nature of the impact varied according to discipline and institution (51).
sector, including: i) strong and committed leadership; ii) active involvement of the medical director; iii) availability of a nurse with palliative care expertise to guide and support the implementation; iv) presence of an onsite champion; v) combining a ‘bottom up’ and ‘top down’ approach to organisational change; vi) implementing change in small manageable increments; vii) inclusion of all staff in the effort; viii) regular meetings where discussions of palliative care occur; ix) maintenance of dying residents within the existing unit structures; and x) capacity to use the program as a benchmark of quality care and regulatory compliance\(^{30}\).

Wherever possible the principles of palliative care need to be embedded in the care culture, which makes the provision of stand alone education unlikely to be sufficient to bring about sustainable changes in practice\(^{4}\). To maximise impact, any educational initiative needs to be undertaken in conjunction with other target interventions that address the organisational culture of the residential aged care facility\(^{4, 30}\).

### 5.6 Appraising the literature to guide the development of an intervention

This integrative literature review identified a number of factors as critical in implementing an effective learning and development intervention for aged care nurses and care assistants. These include: action learning as a process of reflection and development\(^{56, 57}\); embracing the concept of lifelong learning\(^{58}\); the importance of evidence based practice\(^{59, 60}\); increasing coordination and communication across sectors \(^{61-63}\); reducing professional isolation\(^{1, 47}\); and data to drive quality improvement\(^{64, 65}\).

#### 5.6.1 Action learning – a process of reflection and development

Action learning implies that a group of people come together to mutually derive a solution to a problem or issue\(^{56, 57, 66}\). This process is in contrast to more traditional pedagogical approaches which are often hierarchical and hegemonic\(^{67}\). Action learning is a dynamic process of learning and reflection to achieve a desired goal. Reflection is a key element of any learning as it links thoughts with action and in the process promotes greater awareness and understanding\(^{68, 69}\). Although it is assumed to occur spontaneously, most learners require prompting, support and practice to engage in reflective practice\(^{69, 70}\). Action learning achieves its outcomes by harnessing the process of group dynamics and identifying the unique attributes and potential contributions of participants\(^{56, 57}\). Action learning is considered to be
a preferable model for increasing competencies in the residential aged care setting where many clinicians are involved in the care of the resident\(^{(57)}\).

### 5.6.2 Embracing the concept of lifelong learning

Learning for adults is a complex, multifaceted and lifelong process\(^{(58)}\); it is based on the premise, that unlike children, adults are autonomous and capable of self-directed learning\(^{(71)}\). Most adults enter a learning experience in order to live more effective lives by creating a change in their knowledge, skills, behaviour or attitudes\(^{(58)}\). In reviewing the concept of lifelong learning, Boud\(^{(70)}\) established that four major traditions of adult learning were evident in the literature, each with their own strengths and weaknesses. These are discussed below.

**Training and efficiency in learning**

A training and efficiency in learning approach is underpinned by cognitive psychology\(^{(70)}\). This approach aims to make the acquisition of new knowledge and skills as easy as possible for the learner through the use of a traditional authoritative teaching format\(^{(70)}\). A limitation of this approach is that it assumes that the learner will respond positively to the educational material provided, so there is limited scope to address an individual’s unique learning needs\(^{(70)}\).

**Learner-centred education**

Learner-centred education is evident throughout Carl Rodger’s work\(^{(70,72)}\). This approach values and respects’ individual learners\(^{(70)}\). It aims to ensure that individuals are supported to identify their own learning needs and acknowledges that for some learners this can be a challenging process\(^{(70,72)}\). This approach encourages learners to express their ideas, to be confident to seek assistance from others and supports them to develop an individual learning plan that will address their unique educational needs\(^{(70,72)}\).

**Self-directed learning**

A self-directed learning approach emerged largely in response to the traditional authoritative teaching format and builds upon Carl Rodger’s work\(^{(70,72)}\). Malcolm Knowles is largely credited with developing this approach which is based on a set of assumptions about adult learners\(^{(58,71)}\). These assumptions suggests that as: people mature they become more self-
directed learners; an accumulation of life experiences are a rich resource for learning; a readiness to learn becomes increasingly aligned to one’s social roles; over time, learning is more likely to occur if new knowledge is immediately applicable; and with maturation, the motivation to learn becomes internalised\(^{58, 71}\).

**Critical pedagogy and social action**

The work of Paolo Freire exemplifies a critical pedagogy and social action approach to education\(^{73, 74}\). This approach suggests that learning is shaped by history, material and social contexts\(^{70}\). Education is viewed as a tool for social and political change which has the potential of addressing the social and physical environments that act to constrain learning\(^{70, 73}\). Learning is not simply about knowledge and skill acquisition but is an enriching process that aims to lead to social or political change\(^{70, 73}\). This change occurs when the learner is supported to reflect and understand their position in society, can identify how this limits their goals and learning and is able address these restrictions through a range of targeted actions\(^{70}\).

**Other considerations**

Regardless of the philosophical basis, the participants are the principle players in the teacher-learning transaction in adult education with the teacher acting as a guide who facilitates learning\(^{70, 72}\). To be effective, participation in adult education must be voluntary and reflect participants’ past experiences and/or current issues\(^{75}\). Facilitation of learning requires a multifaceted, flexible approach, which enables learning to occur in both formal and informal learning settings\(^{70}\). It should be noted that the context of the setting can act to both provide and constrain learning opportunities\(^{70}\).

Lifelong learning is imperative for the professional development of all workforces. Nursing competencies are dependent upon acquiring knowledge and skills through experiential and formal knowledge. In the aged care sector, lifelong learning assumes critical importance given the limited educational preparation of care assistants and the challenges of recruiting highly skilled nurses\(^{16, 21}\). Without lifelong learning, there is a risk that aged care knowledge could become obsolete, fixed and impervious to new ideas\(^{76}\).
An adult education perspective embedded within an action learning framework in the R-PAC Project enabled participants to draw upon their shared histories, values and knowledge in order to derive meaning from their life experiences. In the process, participants were provided with an opportunity to redefine their internally held beliefs about palliative care and to develop collective solutions to problems\(^{(77)}\). Yet in spite of the emphasis on the individual, there is also a need to consider contextual factors and policy frameworks. In order to deliver appropriate care it is necessary that this is based upon the best available evidence.

### 5.6.3 The importance of evidence based practice

Evidence based practice has emerged as a key driver for health care reform\(^{(59, 78-80)}\) and has been defined as the:

> … conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine also means integrating individual clinical expertise with the best available external clinical evidence from systematic research\(^{(81)}\) (p.71).

Evidence based practice has the potential to address inconsistencies in care and to improve care delivery, regardless of care setting\(^{(82)}\). Implementing evidence based practice requires health care providers to have the necessary skills to review and evaluate the levels of evidence. Appraising the levels of evidence is critical because it reflect the study design and signify the degree to which the design has been able to eliminated bias (Table 5-5)\(^{(83)}\).

The translation of research into practice is influenced by: the level and nature of the evidence; the way the process is facilitated; and the context in which the evidence is placed\(^{(85, 86)}\). Numerous barriers have been identified that may prevent the adoption of evidence based practice, including limited: time and/or availability of relevant research; access to peer reviewed journals; search skills and research appraisal competencies; administrative support; as well as negative attitudes towards research and a perception that it is costly and has the potential to detract from clinical work\(^{(82, 87-89)}\). All of these issues are particularly prevalent in the aged care setting\(^{(82)}\). Consequently, some care in a variety of settings, including aged care, is currently not based on evidence based practice but informed by tradition, provider and/or patient preference and institutional practice\(^{(82)}\).
In an attempt to address this anomaly, Standards for Aged Care\(^6\) have been developed. However, neither the Standards for Aged Care\(^6\) nor the Palliative Care Standards\(^7\) acknowledges the unique and often complex palliative care needs of older people in aged care. The publication of the ‘Guidelines for a palliative approach in residential aged care’\(^5\) emerged in response to this identified need. Internationally, these guidelines are the first of their kind and in late 2005 the 2\(^{nd}\) edition was endorsed by National Health and Medical Research Council until September 2010\(^8\). These guidelines contest or support existing practice in aged care facilities and make numerous recommendations to guide practice change\(^8\); they are designed to assist aged care facilities develop and apply suitable policy and procedures\(^3\). Despite the widespread distribution of these evidence based guidelines\(^5\), it is known that guidelines alone, like education, rarely result in behaviour change\(^4,9\) and that changing clinical practice is a complex process that requires a multifaceted approach\(^8,8\). Regardless of this, the access to these guidelines was a significant impetus to the R-PAC Project.

### 5.6.4 Reducing professional isolation

The ethos of health care services varies, with the non-profit age care sector being underpinned by principles of ‘altruism’ whilst the for-profit aged care sector operates as an ‘industry’ and is driven by business profit goals. These differing philosophies and business structures act to isolate aged care providers from one another, and as a consequence they rarely network or

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**Table 5-5: Levels of quantitative evidence**

<table>
<thead>
<tr>
<th>Levels</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Systematic review of all relevant randomised controlled trials (RCT)</td>
</tr>
<tr>
<td>II</td>
<td>At least one properly designed randomised controlled trial</td>
</tr>
<tr>
<td>III-1</td>
<td>Well designed pseudo-RCT</td>
</tr>
<tr>
<td>III-2</td>
<td>Comparative study with concurrent controls and allocation not randomised, case-control studies or interrupted times series with a control group</td>
</tr>
<tr>
<td>III-3</td>
<td>Comparative study with historical controls, two or more single arms studies, or interrupted time series without a parallel control group</td>
</tr>
<tr>
<td>IV</td>
<td>Case series, either post-test or pre-test and post-test</td>
</tr>
</tbody>
</table>

*Source: National Health and Medical Research Council\(^8\) (p.20)*
have an opportunity to share in professional activities. By virtue of their industry status, aged care providers operate in relative isolation from other health care providers and this has been recognised as a barrier to effective care\(^{(1,47)}\).

### 5.7 Key considerations for the R-PAC Project

At a local level, a combination of professional isolation\(^{(1)}\) and aged care nurses’ lack of awareness of local palliative care resources\(^{(91)}\) suggested that opportunities to establish networks and rapport with the specialist palliative care team were required. Having an understanding of other health care providers’ roles and expertise across the care continuum underpins effective multidisciplinary networking\(^{(92)}\). Yet, there are few examples of palliative care networks being established through systematic processes and very often those that do exist appear to have been triggered by a specific need\(^{(93,94)}\). Despite this concern, the Critical Reference Group felt that creating local networking opportunities would foster greater communication between the aged and palliative care teams. In turn, this may help to ensure that aged care nurses feel more confident about seeking expert advice as required from the specialist team.

#### 5.7.1 Exploring the capacity of the specialist palliative care team

Consultations with the local specialist team revealed that their workload had prevented them from supporting local residential aged care nurses and care assistants to increase their palliative care competencies\(^{(93)}\). This is in accordance with the literature, which suggested that, at the commencement of the R-PAC Project, less than half of all specialist palliative care teams in Australia had engaged in educational initiatives with the aged care sector\(^{(95)}\). Despite staff shortages and workload pressures, the local specialist palliative care team were keen to partner with aged care providers to provide appropriate learning opportunities for aged care nurses. The specialist palliative care team suggested that field placements would offer aged care nurses a chance to network and establish rapport with the team, observe the specialist team in operation and provide action learning opportunities. In addition, the specialist team indicated that they were available to provide specialist input into the management of residents with complex care needs, through consultations or via the multi-agency, multidisciplinary team meeting. However, it was suggested that this additional workload would effectively limit the specialist team’s ability to participate in other health care provider education during 2005. This issue was explored with the team’s manager who supported their stance and...
endorsed their desire to focus on enhancing the palliative care capacity of local aged care providers. In addition, the specialist palliative care team recommended that if field placements were implemented, that they be conducted on the day that the multidisciplinary meeting was held and at a time when the visiting palliative care physician was conducting a clinic.

5.8 Using PRECEDE to map out the multifaceted intervention

Having appraised the literature to guide the development of the intervention it was time to return to the PRECEDE framework and undertake the administrative and policy diagnosis, as detailed in Chapter Two. This phase of PRECEDE involved an analysis of the policies, resources and the prevailing organisational circumstances that could facilitate or hamper the implementation of the R-PAC Project’s multifaceted intervention\(^2\) (Table 5-6). A range of administrative and policy issues were identified that needed to be factored into the development of any intervention, including: time constraints for aged and palliative care personnel; the challenges associated with change and the need for a clinical champion in each facility; the degree to which aged care facilities could cope with change given other dynamics, such as staff shortages, accreditation schedules, and commissioning of new beds; and other initiatives.

The needs assessment data, literature review and the findings from the PRECEDE frameworks administration and policy diagnosis phase informed the multifaceted intervention developed by the Critical Reference Group. This intervention was subsequently endorsed by the Aged Care Professionals Group and Project Advisory Group who made funds available to support its implementation. The key premises of the multifaceted intervention were a desire to partner with clinicians in residential aged care to increase access to and quality in a palliative approach by creating an enabling and empowering learning environment. The strategies employed included increasing access to specialists’ resources and evidence based information through the creation of: a link nurse role; increased learning and development opportunities for nurses, care assistants and general practitioners; and the promotion of networking and multidisciplinary care. A summary of the key elements of the R-PAC Project’s multifaceted intervention are provided in Table 5-7.
<table>
<thead>
<tr>
<th>Administrative and policy issues</th>
<th>Importance</th>
<th>Changeability</th>
<th>Total</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to establish change champions in each local aged care facility</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Need to engage all levels of aged care personnel in the change process</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Need to acknowledge the unique learning needs of nurses, care assistants and general practitioners</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Need to utilise external experts to implement the learning and development initiatives and develop program material</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Staff shortages and cost limit the degree to which local aged care facilities can support nurses and care assistants to engage in palliative care learning and development initiatives</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Aged care nurses’ and care assistants’ commitment and attitudes towards a palliative care learning and development intervention</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Potential for policy conflict between actual palliative care practice in local aged care facilities and best evidence based practice</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Rate at which local aged care facilities can implement policy change to enhance palliative care delivery</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>The degree to which a palliative approach is consistent with local aged care facilities existing policy and organisational mission</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Time and resources limit the capacity of the specialist palliative care team to engage in multiple initiatives with the local aged care sector</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Other organisational issues (staff shortages, recruitment, accreditation, increasing bed numbers etc) occurring concurrently</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

**Key:** Low = 1, Medium = 2, High = 3
Table 5-7: Summary of R-PAC Project’s multifaceted palliative care intervention

<table>
<thead>
<tr>
<th>Key Elements</th>
<th>Target Group</th>
<th>Learning and development strategy</th>
<th>Target</th>
</tr>
</thead>
</table>
| Tailored learning and development intervention | Link Nurses | 24 hour palliative skill development workshop  
16 hour field placement with the specialist palliative care team.  
2 hour bi-monthly peer support meetings.  
Option to enrol in an accredited palliative care module and receive 10 credit points towards a post-graduate diploma in palliative care | 1 Link Nurse per 50 aged care beds |
| | Registered Nurses | 2 day palliative care skill development workshop | 1 additional RN per aged care facility |
| | Care Assistants | 16 hour palliative care skill development workshop  
Opportunity to network with other care assistants from local RACFs  
Opportunity to meet with: Specialist Palliative Care Team and Aged Care Assessment Team, and Link Nurse from their RACF | 150 Care Assistants |
| | General Practitioners | 8 hour palliative care field placement with the specialist palliative care team, including: attending the multidisciplinary care planning meeting, specialist outpatient clinic and home visits | 22 General Practitioners |
| Participation in Specialist Palliative Care Multi-agency, Multidisciplinary Team Meeting | Link Nurses, Registered Nurses, General Practitioners | Attendance at the multidisciplinary team meeting during all field placement  
Action learning opportunities  
Networking opportunities  
Opportunity for residents with complex palliative care needs to have their care planned by the multidisciplinary team | All link nurses and general practitioners |
5.9 Developing the link nurse role

The link nurse concept has been used in the UK in infection control, diabetes, wound care, stoma care and palliative care\(^{52, 94, 96, 97}\). The advantages of a link nurse model is that it enables an organisation to actively invest in a small number of registered nurses who are prepared to commit to take on an additional role in a sub-specialty and act as ‘clinical champions’ within the aged care facility\(^{25, 96}\). In order to facilitate intervention development and implementation, the link nurse role\(^{25, 52}\) was considered to be critical for not only the intervention, but also to promote sustainability\(^{25, 51, 97}\). The literature and the needs assessment data guided the Critical Reference Group in the development of the link nurse role, which is summarised in Table 5-8.

**Table 5-8: Palliative care link nurse role**

<table>
<thead>
<tr>
<th>Link nurse role</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>To liaise with the specialist palliative care team on aspects of palliative care and to facilitate the dissemination of palliative care guidelines, policy and information to peers, and where appropriate, to residents and their families</td>
<td></td>
</tr>
<tr>
<td>To assist in the education of aged care nurses and care assistants in a palliative approach</td>
<td></td>
</tr>
<tr>
<td>To ensure that there is compliance with the delivery of a palliative approach to care for residents and their families</td>
<td></td>
</tr>
<tr>
<td>To attend bi-monthly link nurse meetings and an annual education day</td>
<td></td>
</tr>
<tr>
<td>To liaise with the director of nursing with regard to the implementation of a palliative approach within the facility</td>
<td></td>
</tr>
<tr>
<td>To promote the integration of a palliative approach into relevant organisational policy</td>
<td></td>
</tr>
</tbody>
</table>

_Source: Adapted from Roberts and Casey\(^{96}\)._

In adopting this concept, it was acknowledged by the Critical Reference Group that it was inevitable that over time the link nurses would resign or be redeployed and the challenge would be to replace these nurses with additional, suitably skilled nurses. A strategy would be needed to ensure the ongoing replacement and training of new link nurses and to develop the palliative care competencies of all registered nurses employed in the aged care sector. In spite of these potential threats, the Critical Reference Group decided to proceed with the adoption of the link nurse concept.
The Critical Reference Group collaboratively developed a tailored learning strategy to prepare registered nurses for their link nurse role that included: i) an intensive palliative care knowledge and skill development course; ii) a two day field placement with the specialist palliative care team; iii) opportunities to participate in the specialist palliative care multidisciplinary care planning meeting; and iv) development of opportunities to increase confidence to conduct in-house palliative care education.

It was estimated that this strategy would equate to a minimum of forty hours of educational time. As this represented a significant investment for both aged care management and the specialist palliative care team, further key stakeholder consultation was undertaken to identify aged care providers’ capacity to support this proposal. Importantly, all nine directors of nursing enthusiastically endorsed the proposed link nurse learning and development strategy and indicated a willingness and ability to support nurses’ participation in this initiative, as did the specialist palliative care team. This support enabled the Critical Reference Group to proceed to implementing the link nurse learning and development strategy with confidence.

A link nurse recruitment process was collaborative developed by the Critical Reference Group. Expressions of interest were sought from registered nurses working for more than 16 hours per week in a local residential aged care facility who had a demonstrated interest in palliative care (Appendix 9). All intending applicants were required to seek endorsement from their director of nursing before applying in writing. A total of 14 applications were received, all met the selection criteria and were supported by their director of nursing to become the facilities palliative care link nurse. In one facility there was an excess of applications, with the director of nursing making a decision as to who the link nurses would be. Importantly, other palliative care learning opportunities were afforded to the unsuccessful applicants.

The two day link nurse workshop was contracted to an external organisation based in Queensland with experience in providing palliative care education to the aged care sector\(^{(98)}\). This organisation delivered the course content as stipulated by the Critical Reference Group (Appendix 10). A variety of teaching strategies underpinned by the principles of adult education\(^{(99)}\) were incorporated into this course. The link nurse course was conducted in a local aged care facility’s education centre, in October 2004. The two day palliative care field placements and bi-monthly peer support meetings commenced in December 2004 and were completed by December 2005. All registered nurses who completed the link nurse course...
were eligible to enroll in a palliative care module at a significantly reduced rate and receive 10 credit points towards a Graduate Certificate in Clinical Nursing\(^{(98)}\). Two aged care nurses subsequently enrolled and completed this certificate.

The link nurses’ field placements with the specialist palliative care team were arranged for the day that the specialist palliative care service held their weekly multidisciplinary team meetings. Once a fortnight, the visiting palliative care physician attended this meeting whilst conducting an outreach service to Coffs Harbour. On the first day of the field placement, the link nurses observed the palliative care clinical nurse consultant conducting in-patient palliative care nursing consultations. During the second day of the field placement the link nurses were provided with an opportunity to observe the palliative care nurse specialists visiting patients and their families at home and liaising with other health care providers.

At the request of the link nurses, their final education day of the five day format was focussed on the principles of adult education. This education session aimed to increase the confidence of link nurses to implement palliative care education within their aged care facility. It was scheduled to occur in late 2005 by which time all of the link nurses would have completed their palliative care field placements. Unfortunately, inadequate staffing ratios in both aged care and palliative care along with additional educational commitments for aged care personnel delayed this education day from occurring until September 2006 (Appendix 11). There had also been several changes in the link nurses status, due to resignations and redeployment to other aged care facilities. At the end of the R-PAC Project in December 2006, 10 of the original link nurses were still active in the role, and two of the three link nurse vacancies due to resignations, had been subsumed by registered nurses’ who had completed the palliative care education course. The specialist teams’ commitments to general practitioner education in 2006 limited opportunities for these replacement link nurses to undertake a palliative care field placement with the specialist team before the completion of the R-PAC Project.

5.10 Meeting the learning needs of care assistants

As previously noted, care assistants form the bulk of the aged care workforce and are largely untrained and unregulated workers\(^{(17)}\). There is considerable diversity in skills and previous work and life experiences amongst this group of aged care workers. This heterogeneity suggested that an educational strategy was required that was able to meet care assistants’
specific learning needs in palliative care. This education needed to build upon their previous life experiences and validate their roles while acknowledging their scope of practice. The needs assessment data and Critical Reference Group recommendation were that the focus of the learning and development strategy be on enhancing care assistants’ palliative care clinical assessment competencies and communication skills. A 16 hour palliative approach course was developed by the Critical Reference Group based on the palliative approach competency guidelines\(^{100}\) (Appendix 12).

In addition, a structure was required that would maximise care assistants’ access to a tailored palliative care learning and development strategy. The advice of the Critical Reference Group helped to maximise the appeal of the learning and development strategy developed for care assistants, by ensuring that its content and structure was best suited to their learning needs. A range of adult learning strategies were incorporated into this course, including: lectures, small-group discussion, group work, role plays, case studies and reflective practice exercises\(^{58, 98}\).

This course commenced in early 2005 and was facilitated by an experienced palliative care clinical nurse consultant with extensive vocational education experience having previously conducted TAFE courses for care assistants. Six courses with the capacity to provide learning and development opportunities for up to 150 care assistants and enrolled nurses were scheduled for 2005. The course was conducted at an education centre at a local aged care facility and was open to all care assistants and enrolled nurses currently employed in one of the nine local aged care facilities. There was no fee for participating in the course.

On the final day there was a session in which all participants met with a link nurse based at their aged care facility. This session was designed to enable the care assistants and link nurses to identify an area for action within their aged care facility to address collaboratively; it also aimed to assist with promoting greater collaboration, communication and to enhance networking. All participants who completed the 16 hour palliative approach course were presented with a certificate of competence. Participants who missed sessions and wanted to complete the course were provided with an opportunity to attend a corresponding session in the next course.

5.11 Engaging registered nurses

It an effort to increase the palliative care competencies of the aged care work force it was acknowledged that, in addition to the link nurse positions, there was a need to develop a
palliative care learning and development strategy targeting other registered nurses employed in aged care. The Critical Reference Group suggested that this learning and development strategy should be based on the two day course developed as part of the link nurse strategy. Process evaluation data obtained from the link nurses course led to some modifying of the format of this two-day workshop, which included a challenging communication role play based on a palliative aged care scenario, a session on advance care planning and strategies to integrate spiritual care into nursing practice (Appendix 13). The learning and development strategy for registered nurses was conducted during late 2005. This workshop was facilitated by a palliative care clinical nurse consultant, with extensive adult education experience.

5.12 Creating an in-house palliative approach team

At the outset of the R-PAC Project it was intended that the action research process would also be carried out and driven by a small group of aged care providers within each facility, as illustrated in Figure 5-1. As the learning and development strategy progressed there would be increasing numbers of aged care personnel with palliative care competencies in each facility enabling the establishment of in-house palliative approach teams. Each in-house team was supported to collaboratively identify priorities for action that would assist to embed the palliative approach evidence based guidelines within their aged care facility.

**Figure 5-1**: Organisational overview of the in-house palliative approach teams
5.13 Involving general practitioners

The general practitioner plays a key role in the delivery of primary care, including palliative care, to people at home and in the residential aged care setting\(^{(101, 102)}\). Despite general practitioners in rural areas seeing more palliative care patients than their urban counterparts, it is still hard for these doctors to maintain their palliative care competencies as they typically only see 4-6 patients per year in the palliative phase\(^{(103)}\). This limited exposure makes it difficult to remain abreast of emerging trends in this speciality\(^{(104)}\).

The challenges of engaging general practitioners in palliative care learning and development activities is well documented\(^{(103, 105-107)}\). In Coffs Harbour LGA there are some 80 general practitioners, few of whom work on a full-time basis, which has exacerbated workloads due to a shortage of local doctors\(^{(108)}\). Consequently, local general practitioners’ involvement in the delivery of palliative care and aged care locally is quite variable\(^{(1, 93)}\). Previous research has identified that any palliative care education strategy targeting general practitioners needs to: i) take into account their variable skill level and interest in palliative care, ii) reinforce their core skill set, iii) be opportunist case based education underpinned by adult education learning principles, iv) be accessible and available locally, and v) provide financial support to renumerate them for lost work time\(^{(104, 109, 110)}\). All of these challenges suggested developing an effective learning and development strategy for general practitioners would require careful consideration and planning\(^{(111)}\). This finding prompted the Critical Reference Group to pause in order to collect additional information and data about the learning and development needs of general practitioners before progressing further.

5.14 Engaging link nurses in the specialist multidisciplinary team meeting

Multidisciplinary care is the cornerstone of effective palliative care and is a vehicle for providing an integrated team approach to care\(^{(112)}\). Multidisciplinary care occurs when medical, nursing and allied health professionals consider all treatment options, including all of the potential benefits and disadvantages of treatment decisions and personal preferences of the patient\(^{(112)}\). These health professionals then collaboratively develop an individual care plan that best meets each person’s needs\(^{(112)}\). At the time of the R-PAC Project, the local specialist palliative care service were expanding their weekly specialist multidisciplinary team meeting to become a multi-agency forum open to generalist providers caring for palliative care patients in the community and acute care sector\(^{(113)}\). This development provided a unique opportunity
for aged care nurses to participate in this care planning forum, which would ensure that residents with complex care needs had their care appropriately appraised\(^{50}\). Further, it was also considered that this strategy would help to strengthen relationships between aged and palliative care services, provide action learning opportunities and model inter-disciplinary collaboration.

### 5.14.1 Staged implementation of the multifaceted intervention

A pragmatic decision was made to implement the multifaceted intervention in stages to balance the resource needs of aged care providers and the palliative care team (Table 5-9). Establishing the link nurse’s role within each facility was the Critical Reference Group’s first priority, closely followed by enhancing care assistants’ palliative care competencies. Once this had been completed, the focus would move to implementing learning and development opportunities for registered nurses, whilst the field placements for general practitioners would be held over until 2006. It was decided that the learning and development strategies would be implemented by external educational providers and that each residential aged care facility would be responsible for determining the rate at which the palliative approach guidelines were reflected in policy documents and practice.
Table 5-9: The R-PAC Project’s multifaceted intervention timeline

<table>
<thead>
<tr>
<th>Target Group</th>
<th>Timeline</th>
<th>Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link Nurses</td>
<td>Oct 2004</td>
<td>2 day Palliative Approach Course</td>
</tr>
<tr>
<td></td>
<td>Nov 2004 – Dec 2005</td>
<td>2 day field placements with specialist palliative care team</td>
</tr>
<tr>
<td></td>
<td>Oct 2004 – Dec 2006</td>
<td>Bi-monthly peer support meetings</td>
</tr>
<tr>
<td></td>
<td>Oct 2005</td>
<td>One day workshop - applying adult education principles to palliative care in RACFs</td>
</tr>
<tr>
<td>Care Assistants</td>
<td>Jan 2005 - Dec 2005</td>
<td>Six, 16 hour Palliative Approach Workshops</td>
</tr>
<tr>
<td>Registered Nurses</td>
<td>Sept 2005</td>
<td>Two day Palliative Care Workshop</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>Jan 2006 – Dec 2006</td>
<td>One day field placements with the specialist palliative care team</td>
</tr>
</tbody>
</table>

5.15 Measuring the reach of the multifaceted intervention

By the end of Phase Two of the R-PAC Project 35% (n=157) of the total local aged care workforce (n=444) had been engaged in the learning and development strategies (Table 5-10). The participation rates in the tailored learning interventions, included, 36% (n=116) of all care assistants, 32% (n=12) of all enrolled nurses and 32% (n=29) of all registered nurses employed in the nine aged care facilities. All nine aged care facilities participated in the multifaceted intervention with varying levels of participation as illustrated in Figure 5-2.
Table 5-10: R-PAC Project’s participation rates by facility and discipline

<table>
<thead>
<tr>
<th>Bed Numbers</th>
<th>Aged Care Facility</th>
<th>Link Nurse</th>
<th>Registered Nurses</th>
<th>Enrolled Nurses</th>
<th>Care Assistants</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>134</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>19</td>
<td>29</td>
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<tr>
<td>51</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td>74</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>24</td>
<td>32</td>
</tr>
<tr>
<td>75</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>75</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>56</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>49</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>38</td>
<td>8</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>46</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>598</td>
<td>Total</td>
<td>13</td>
<td>16</td>
<td>12</td>
<td>116</td>
<td>157</td>
</tr>
</tbody>
</table>

Figure 5-2: Participation rates in the multifaceted intervention by facility and role
The R-PAC Project successfully established a link nurse role in all nine aged care facilities (100%) achieving the target of one registered nurse per 50 aged care beds with palliative care knowledge and skills. At the end of the R-PAC Project 77% \((n=10)\) of the link nurses were still active in this role. There was an 85% \((n=128)\) success rate in ensuring that 150 care assistants and/or enrolled nurses completed the 16 hour palliative approach workshop. However, the performance indicator set by the Critical Reference Group, that 50% of care assistants employed in Coffs Harbour’s nine aged care facilities would complete the palliative approach workshop wasn’t achieved, with only 36% \((n=116)\) of the total care assistant population completing this course. This result may partially be explained by a 14% \((n=39)\) increase in the number of care assistants employed over the course of the R-PAC Project. Although all of the palliative approach workshops were fully subscribed there was a 15% \((n=22)\) attrition rate, largely due to extenuating personal circumstances, which has impacted on the overall care assistants completion rates.

There was also evidence of changes in care delivery patterns, with 18% \((n=73)\) of all residents who died having their palliative care planned at the specialist palliative care multidisciplinary team meeting during the period of the R-PAC Project. The number of residents’ who died increased by 13% \((n=26)\) over this period from 169 deaths in 2003 to 195 deaths in 2005. There was an increase in the number of residents who had their end-of-life care managed within local aged care facilities from 79% \((n=133)\) in 2003 to 85% \((n=165)\) in 2005. Despite this improvement, this increased rate didn’t meet the 90% target set by the Critical Reference Group.

**5.16 Assessing the impact and seeking direction**

As detailed in this chapter, the second phase of the R-PAC Project’s action research process focused on developing, implementing and monitoring the multifaceted intervention. As this phase of the action research cycle drew to a close, there was evidence to suggest that the multifaceted intervention had made significant progress towards achieving its overall objectives, but this required further exploration. The Critical Reference Group also wanted to gain a greater understanding of the impact of this multifaceted intervention and to seek direction for the next stage of the R-PAC Project. In order to further explore these issues, a series of focus groups were undertaken with aged care nurses and care assistants (Study E) and General Practitioners (Study F) to elucidate this information. These studies are discussed in the following chapter.
5.17 Reference list


39. Grbich, C., Maddocks, I., & Parker, D. (2003). *Palliative care in aged care facilities for residents with non-cancer diagnosis.* Adelaide: Department of Palliative and Supportive Services, School of Medicine, Flinders University.


79. Palliative Care Australia. (2005). *Standards for providing quality palliative care for all Australians.* Canberra, ACT.


Chapter 6.

Reflecting on the Action:
Exploring Perceptions and
Discovering the Common Ground
There is nothing more difficult to carry out, nor more doubtful of success, nor more dangerous to handle than to initiate a new order of things’ Machiavelli ‘The Prince’

6.1 Introduction

As discussed in Chapter Five, a multifaceted learning and development intervention informed by empirical methods was developed by the Critical Reference Group. At the end of Phase Two of the action research process, it appeared that the multifaceted intervention was being successful in attaining the R-PAC Project’s objectives. In order to inform the future direction of the R-PAC Project, the Critical Reference Group felt a greater understanding of the impact of this multifaceted intervention was required along with determine enabling and inhibiting factors. It was also established that aged care personnel and general practitioners needed to have input into the direction of the next phase of the R-PAC Project.

This chapter describes the method and findings of focus groups undertaken with aged care nurses and care assistants (Study E) and general practitioners (Study F). Although the purpose of the focus groups with aged care personnel and general practitioners were to seek their views on implementing a palliative approach, these two tracks of exploration are reported separately. This was taken because interviews with the aged care personnel had a greater focus on exploring the process issues relating to the multifaceted intervention, while the focus groups with general practitioners discussed overarching issues in the delivery of a palliative approach. Further, it was decided to conduct these investigations concurrently, yet separately, to allow each of these key stakeholder groups to have a voice within their own professional contexts.

6.2 Study E: Assessing the perceptions of aged care personnel

A focus group methodology was selected at the mid point of the R-PAC Project because it was felt to be a useful way of developing an understanding of participants’ perceptions of the multifaceted intervention. As focus groups have previously been used to develop health service interventions and to inform evaluation strategies, it was anticipated that the data generated would assist in identifying actions to be considered during the third phase of the action research process.
6.2.1 Aim

The aim of this study was to assess aged care nurses’ and care assistants’ perceptions of the impact of a multifaceted palliative care intervention implemented during the second phase of the R-PAC Project’s action research process.

6.2.2 Participants

Each aged care facility was provided with an opportunity to host a focus group, with the first four facilities who responded to this invitation chosen as the focus group sites. Invitations were then sent to all participating aged care facilities inviting aged care nurses and care assistants to join in one of the four focus groups conducted in July 2005. A purposive sample of twenty-eight participants volunteered to contribute to focus groups, which were composed of directors of nursing (n=4), link nurses (n=7), registered nurses (n=8), and care assistants (n=9). The majority of participants (n=20) had participated in the multifaceted intervention.

6.2.3 Data collection

As detailed in Chapter Three, a focus group methodology is a form of group interview that generates data through the thoughts and ideas of individuals and the group collectively\(^8,^9\). The questions for this focus group study were designed to explore nurses’ and care assistants’ perceptions of the multifaceted intervention and to determine the extent to which the intervention had impacted on care practices (Table 6-1).

The same procedure was used as previously described in Chapters Three and Four, with all focus groups being conducted in local aged care facilities, to create a safe environment in a familiar setting and thus facilitate a free and open exchange amongst participants\(^10\). Each of the four focus groups was moderated by the (supervisor) while the assistant moderator (researcher) took detailed field notes, documenting observations and interactions between participants\(^11,^12\). Despite the heterogeneous compositions of the groups from a hierarchical perspective, no one person dominated the focus groups. All participants were respectful of others’ views and actively participated in discussions. Each focus group was audio-taped to allow data verification and validation\(^13\), which allowed for the issues of time and person to be included in the analysis\(^12\). Focus groups were conducted until it was apparent that no new data were being generated and saturation had been reached.
Table 6-1: Focus group question route - aged care personnel

<table>
<thead>
<tr>
<th>Question route</th>
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<tbody>
<tr>
<td>What does the term ‘palliative approach’ mean to you?</td>
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<tr>
<td>We are interested to hear your perspective about what has happened in the past 12 months with regard to palliative care service delivery in your facility.</td>
</tr>
<tr>
<td>As the project has another 12 months to run, we are interested to hear what do you think needs to happen to make the delivery of a palliative approach to care a reality in your facility?</td>
</tr>
<tr>
<td>Are there any other issues that you wish to raise?</td>
</tr>
</tbody>
</table>

6.2.4 Data analysis

The same data collection analysis format was used as described in Chapters Three and Four. In summary, data collection and analysis were undertaken concurrently as reflexive activities, using the thematic content analysis framework described by Burnard to highlight significant themes or concepts. After each focus group, the researchers met for an initial analysis session to reflect on group interactions, in particular identifying and noting non-verbal clues endorsing values, opinions and beliefs and to capture their initial thoughts. These sessions helped in identifying and reaching consensus on recurring patterns and common themes. The analysis of transcripts allowed for further revision, grouping and reduction. To illustrate the themes, quotes were selected and their contexts preserved. The final category coding of the broad analytic themes was verified with study participants.

6.2.5 Findings

The analysis revealed four broad analytic thematic findings: (1) Targeted education makes a difference, (2) A team approach is valued, (3) Assessment tools are helpful, and (4) Using the right language is essential.

Targeted education makes a difference

There was evidence that the learning and development strategy was positively received by participants which was endorsed through their description of numerous encouraging outcomes, regardless of their role, and reflected in their non-verbal cues. Nurses and care
assistants were actively sharing their newly acquired palliative care knowledge and skills with their peers: ‘the girls doing the course have shared (information) with us…’ (care assistant, group 4). Consequently, aged care nurses were now motivated to participate in the learning initiative: ‘Are you going to be doing more courses? ...people are now keen to do it after hearing about the course’ (registered nurse, group 3). Participants suggested that having a greater understanding of palliative care concepts had prompted some individual aged care facilities to change practices: ‘we have introduced de-briefing after deaths...we meet at handover for several days and talk about the death...what worked well...’ (director of nursing, group 3). There was also evidence to suggest that some facilities had acknowledged the value of ‘…memorial services with staff, families and residents’ (registered nurse, group 3), and we are now conducting these on a regular basis’.

These participants were now able to clearly articulate what a palliative approach entailed: ‘...I can see people (staff) really understanding what palliative care means’ (director of nursing, group 1): and. ‘The palliative approach has got a lot better...12 months ago, a lot of the times we were very frustrated, with residents in pain or what ever, ...but it has turned around a lot since then and it is now much better’ (care assistant, group 2). There was an acceptance that a palliative approach to care is indicated on admission to aged care. By adopting this approach participants were now better able to plan and meet their resident’s palliative care needs. Participants were also reaching out to work collaboratively with other providers to address the needs of resident’s with more complex problems, as reflected in the following excerpt:

On Tuesday I had the chance to feel it all coming together... we were able to institute a program of care for the gentleman from the day he arrived. I have been in touch with the spiritual coordinator and I am about to get onto the palliative care girls (specialist palliative care nurses).... So my (link nurse) education has given me the tools to institute a program of care for someone from the moment he walked through the door... whereas we would previously have waited and then looked at his pain, but that would have been about it. What has happened for us is that we are now onto it (a palliative approach) straight way. This man has a terminal illness and what has happened [now] wouldn’t have happened twelve months ago (link nurse, group 3).
There was a unanimous perception that aged care personnel had acquired sufficient palliative care knowledge, skills and confidence to enhance care delivery: ‘The course that staff have done has enabled them to better handle the care of residents’ (director of nursing, group 1); while for others it had confirmed and enhanced their palliative care competencies: ‘…(it) has really validated things we have done…it has pulled it all together’ (link nurse, group 3).

While a combination of new knowledge and greater confidence was perceived to be preventing residents from being inappropriately transferred to hospital for end-of-life care: ‘…staff have more confidence, so the families feel more confident to keep the residence in the facility ’ (director of nursing, group 1). In addition, it was apparent that having greater palliative care competencies had enabled participants to enter into conversations with residents, families and their peers about death and dying: ‘Our carers who have done the course feel more confident about talking about dying’ (director of nursing, group 3). While greater palliative care competencies were perceived to have substantially reduced staffs’ fears about caring for a dying resident: ‘…we had a death on the weekend…and their (care assistants) loss of fear is almost tangible’ (director of nursing, group 1).

The link nurses were enthusiastic and committed to enhancing the delivery of palliative care in their facility but were often daunted by the associated responsibility of this assignment. For some there was an added feeling of isolation: ‘If you are the only link nurse in a facility, it is difficult’ (link nurse group 2). There was also evidence that the link nurses felt they needed to consolidate their own palliative care competencies before feeling confident about sharing their knowledge with others in formal education sessions. The care assistants prior to the intervention were not attuned to these issues which may in part explain why some were unaware of the link nurse role: ‘Before the course we didn’t know that there was a link nurse, tools or anything…we just did the showers’ (care assistant, group 2).

Care assistants now felt more confident and empowered to communicate their clinical observations to the nurses. There was a perception that their opinions and observations were now valued and acted upon: ‘…you can make a difference…they (nurses) are now listening to you…I am now aware of the need to speak up and report the changes’ (care assistant, group 4). Care assistants had also gained insight into the valuable role they played within the care team: ‘Empowerment was one of the key things that came from the course…our role is important’ (care assistant, group 3). However, not all participants were as enthusiastic about care assistants having greater palliative care competencies or being empowered. For a minority, one of the unintended consequences of the intervention was that care assistants were
perceived to be challenging the status quo: ‘I’ve had a couple of care assistants’ demand that the nurse do something’ (link nurse, group 1). Although this behaviour was described as challenging, it also highlights that care assistants are taking their advocacy role seriously. Previous research has acknowledged that palliative care education may initially strain or even worsen health care provider relationships but not necessarily on a permanent basis\(^{(16)}\). Unfortunately, insufficient organisational resources had prevented a larger cohort of registered nurses from participating in the intervention, which may have contributed to this situation and it was suggested that: ‘When more registered nurses do the course it will be better...’ (care assistant, group 2). Participants acknowledged that more nurses needed to undertake palliative care education: ‘I would love for all the registered nurses to attend the education’ (director of nursing, group 1).

**A team approach is valued**

The participants now had a greater appreciation of the value of a team approach to care delivery: ‘...working in a team makes a difference’ (care assistant, group 4). There was also evidence of greater collegiality amongst aged care personnel and a belief that teamwork resulted in better care outcomes: ‘The link nurses need your support to get things happening’ (care assistant, group 2). Participants valued the learning and networking opportunity afforded by participation in the specialist palliative care multidisciplinary team meeting, which assisted in reducing their professional isolation: ‘The meetings are very educational...great peer support’ (link nurse, group 1). The data also revealed numerous examples of positive outcomes being derived from having residents with complex problems having their care needs discussed at the palliative care multidisciplinary meeting: ‘... the doctor not prepared to follow recommendations. ...[we]...took the (resident) case to the meeting and the outcome was positive’ (link nurse, group 1).

However, for some nurses, presenting cases at the palliative care multidisciplinary team meeting had been a daunting and disappointing experience: ‘... [I] felt like I wasted their time’ (link nurse, group 1). There was a perception that this response may have emerged as a result of some multidisciplinary team members’ lack of appreciation that a palliative approach was indicated for residents with a life-limiting illness with complex care needs. However, despite some negative experiences, the participants appreciated that a palliative approach for older people in aged care was an emerging paradigm and some members of the multidisciplinary team were still integrating this concept into their daily practice: ‘The (specialist) palliative care team are really starting to open their eyes and now looking out
wider….’ (registered nurse, group 3) and: ‘The focus was (previously) very narrow… pain management, diagnosis…they (specialist palliative care team) appreciate the opportunity to learn from cases outside of the norm’ (nurse, group 1). The participants perceived that increased engagement with the specialist team was mutually beneficial and it was with a sense of pride that these participants described how they believed they were enabling the specialist palliative care team to gain a greater understanding of the unique and complex care needs of older people in aged care: ‘…lots of family problems, literacy issues…lots of good things came from it (MDT) ….The (specialist palliative care) team are on a steep learning curve’ (registered nurse, group 1). There was evidence that engaging with the specialist team was helping to reinforce and value participants’ gerontological competencies and promoting a collaborative approach to care planning.

The ability to participate in the multi-agency, multidisciplinary palliative care team meeting was valued and viewed as being important, but participants expressed concern that time constraints had the potential to limit their ongoing involvement. Consequently, participants expressed the need for their own in-house multidisciplinary team for sustainability issues: ‘We will form a palliative care team and we will have an (in-house) palliative care meeting’ (link nurse, group 1). It was suggested that the establishment of an in-house multidisciplinary team would prevent care decisions from being made in an ad-hoc and reactive manner: ‘…decisions [were previously made] on the run…’ (registered nurse, group 3). Participants felt that all care be planned at a multidisciplinary team meeting (MDT) to foster more appropriate decision making and care planning: ‘It would be good if we developed (MDT meeting) and we got to discuss the needs of all residents’ (nurse, group 3); and ‘…regular case review meetings would be helpful’ (care assistant, group 2). It was suggested that engaging residents and families in the process was an important element: ‘…bringing families into the meeting….There is scope for the families to get a better understanding of the care…’ (registered nurse, group 3).

**Assessment tools are helpful**

The majority of resident care is provided by care assistants who have limited education and training and consequently they often experience difficulties communicating and documenting the subtle clinical changes they observed in residents\(^{17-19}\). Similar to a previous study\(^{16}\), the data revealed that validated assessment tools enabled care assistants to report clinical observations in a systematic manner and in effect gave them a voice: ‘….we can use the tools, then present it [findings] to the registered nurse …if it is written down it is harder to dispute’
Having greater palliative care competencies enabled participants to identify when clinical tools were indicated and gave a sense of facilitating a positive change in the residents’ care: ‘...we like the tools best...if we think someone is in pain we go and use the tool...it has simplified it’ (care assistant, group 2); and ‘If a tool works and brings about change for a resident...we use it’ (care assistant, group 4). Data revealed that the use of validated instruments had enabled pain assessment to become a more objective process and was helping to minimise the impact of individual values and beliefs on care decisions: ‘they (registered nurse) don’t want to medicate people. They cannot accept the pain is real...’I think this person is in pain, nurse’s response ‘No he isn’t’. A lot of these nurses have previous baggage. That’s where tools help...’(care assistant, group 2). The use of pain assessment tools had increased staff’s awareness of the extent of residents’ pain, and was assisting to transform pain management from a reactionary response to a routine intervention: ‘...we didn’t realise they (residents) were experiencing pain during personal care...we now have more people on regular paracetamol...’ (link nurse, group 3); and ‘Since utilising the pain assessment tools...staff are now more attuned to monitoring and reporting pain...’(director of nursing, group 3). There was evidence that the use of validated pain assessment instruments was promoting better pain management practices and an unintended consequence of this practice change was that there was a perception that there were fewer incidents of aggression: ‘Pain can trigger aggressive episodes. Better pain control has reduced these episodes’ (director of nursing, group 3).

**Using the right language is essential**

Participants perceived that having the language of palliative care ensured they were better equipped and more effective in negotiating appropriate care for residents: ‘...better understanding and ability to explain symptoms to the GP’ (link nurse, group 1). Being able to report meaningful findings was impacting positively on care outcomes: ‘We are now more likely to get a regular order (medication) plus a break through order ...we wouldn’t have got this six months ago’ (link nurse, group 3); and ‘We use the (palliative care) medication prompt sheet with the GP...this has been really helpful’ (link nurse, group 3).

Yet, having this language was only effective if other health care providers also had an understanding of this vocabulary: ‘...would have been helpful if the GP knew the palliative care language. GPs need to understand what a palliative care phase classification means...’(link nurse, group 1). There was a perception that this language barrier, if not
addressed between providers, had the potential of causing conflict: ‘We are now better able to express ourselves….but this can be threatening to doctors’ (link nurse, group 1).

6.3 Value of the action research process

The data revealed the value of the action research process in driving clinical practice change\(^\text{(20)}\). The opportunities afforded by the multifaceted intervention were highly valued by management, registered nurses and care assistants. Data revealed that sound leadership had played a key role in enabling and encouraging aged care nurses and care assistants to develop skills outside of gerontology. Further, there was a perception that the multifaceted intervention had helped to organise and equip participating nurses and care assistants with the knowledge, confidence and vocabulary to better negotiate the delivery of evidence-based palliative care for residents. Aged care personnel increased confidence meant that they were now less likely to transfer the resident requiring palliative care. This is an important finding as inappropriate and unnecessary hospitalisation of residents at the end-of-life is often related to inadequate palliative care competencies within the aged care facility, lack of medical support, or family pressures\(^\text{(18, 21)}\). Following the multifaceted intervention aged care personnel also felt more confident about discussing end-of-life care issues with residents and their families. Having the confidence to discuss issues of death and dying with family is a significant predictor for the provision of quality care to dying residents\(^\text{(22)}\).

There was wide acceptance that a palliative approach was indicated from a resident’s admission to aged care and this expansive outlook had enable aged care personnel to move away from the perspective that palliative care was merely restricted to care of the dying. Similar to previous research, education had the greatest impact on care assistants\(^\text{(16)}\). The use of assessment tools was shaping and guiding care assistants’ reporting of clinical observations and helping to mitigate against the conflict that often occurs as a result of differing perceptions related to previous education and training\(^\text{(23)}\). There was a perception that more registered nurses needed to complete the education in order to further embed a palliative approach. This perception needs to be explored further as previous research has noted that limited participation of age care personnel in education initiatives as a significant barrier to enhancing palliative care delivery\(^\text{(24)}\). Despite this limitation, and similar to previous research the palliative care education aged care personnel had undertaken had helped to promote greater team work\(^\text{(16)}\). This team work also included greater engagement of residents and their families in care planning, which is encouraging as it has been noted in the
CHAPTER SIX  

literature that aged care providers often fail to appreciate the importance of drawing on the expertise of families in planning and delivering care\(^{(25)}\). The R-PAC Project’s multifaceted intervention appears to have reinforced the importance of a team approach to care delivery which has been identified as being a critical element of quality end-of-life care\(^{(19)}\).

Earlier research had noted that there was little evidence of a collaborative relationship between palliative care clinicians and aged care providers\(^{(26)}\). Importantly, the intervention had prompted new pathways for aged care personnel and external health care provider, including the specialist palliative care team to work together as care partners. Establishing these links have not only enhanced care delivery, but also assisted in reducing the professional isolation experienced by aged care personnel and increased their access to peer support. The intervention had promoted a more collaborative approach to care delivery by providing valuable insight into the unique contribution that each provider makes to the resident’s care\(^{(23)}\). Having a greater awareness of palliative care principles verified the importance of establishing systems to promote continuity and co-ordination of resident’s care. Creating an in-house multidisciplinary team care planning team was viewed as one potential strategy to enhance care co-ordination.

The implementation of assessment tools, in conjunction with education and training, had helped to removed some of the uncertainty about what is clinically relevant and what needs to be communicated to others and indirectly enhanced team work\(^{(19)}\). For care assistants, being introduced to a range of clinical tools had helped to refine their observational skills and helped them to report their clinical observations in a meaningful format\(^{(17, 27)}\). The existing aged care quality improvement mechanisms are one avenue for ensuring that clinical assessment tools that are more sensitive to the palliative care needs of residents are widely adopted.

Having an understanding of the knowledge, rules and norms, accepted terms and codes, which make up the specialist language of palliative care put care assistants on a par with other health care providers\(^{(28)}\). This new knowledge had enabled aged care providers to join conversations and play a key role in determining residents’ care. Nurses and care assistants now had “a voice at the table”, which helped to increase their personal confidence and fostered a sense of worth and satisfaction.

The data suggested that the role and scope of the link nurse role needs further refinement and that additional strategies were required to increase the number of aged care nurses with
palliative care competencies. Measuring the degree to which the palliative approach guidelines are impacting on the provision of residents’ care will assist in identifying gaps in clinical care and help to evaluate the effectiveness of the multifaceted intervention. As education alone rarely results in sustained organisational change\(^{(29)}\), there is a need to further enhance the capacity of aged care personnel to deliver a palliative approach through system change.

6.4 Making the transition towards a palliative approach

Data revealed that using a multifaceted intervention as the agent of change had helped initiate nurses’ and care assistants’ transition towards the delivery of a palliative approach. Organisational support appears to have been an important factor underpinning many of the perceived changes noted in the finding, including: aged care personnel participation in the palliative care learning and development strategies and palliative care multidisciplinary team meeting; adopting of the link nurse concept, establishing of facility-based memorial services, initiating debriefing sessions and use of validated assessment tools.

The extent to which these focus group findings represent the total nurse and care assistant population needs to be considered given the sample size. The disclosure of a range of views and experiences, revealing both positive and negative attributes of the intervention, suggested a good representation of perspectives. Further participants reflected the scope of practice in residential aged care. Further research is needed to evaluate the effectiveness of this multifaceted intervention, particularly the link nurse role and the degree to which new knowledge has been translated into clinical practice. In addition, these findings presented are clearly aged care providers’ perceptions and may not necessarily reflect those of other health care workers, residents or family. Despite these limitations it is encouraging that aged care providers now desire to create more collaborative models of care delivery as a strategy for further embedding a palliative approach.

6.5 The role of the general practitioner in a palliative approach

The medical skills required to provide effective palliative care mirror those of good general practice care\(^{(30)}\). General practitioners are in the unique position to provide palliative care because of their position within in the health care system, their generic medical competencies and their historical knowledge of patients, their care givers and social circumstances\(^{(31)}\).
Palliative care delivery is a core role of general practice and this is now being acknowledged by a range of professional organisations\(^{(31, 32)}\). Despite the general practitioner being ideally placed to provide palliative care, a range of structural, knowledge and service barriers have been identified that limit general practitioners’ participation in palliative care delivery\(^{(30)}\). These barriers have been amplified by the unclear role of the general practitioner in a specialist palliative care environment\(^{(30)}\). The proliferating of specialist palliative care services during the late 1980’s early 1990’s has promulgated the notion that care of the dying ought to be relegated to the specialist, rather than be left to generalist providers\(^{(31)}\). This notion has created role ambiguity for general practitioners and, at times, professional rivalry between health care providers\(^{(33)}\). However, the reach of these specialist services is very limited, with the majority only servicing patients with malignancy\(^{(34, 35)}\). This limitation has raised questions about equitable access, efficient utilization of scarce resources and a need to extend the reach of palliative care to people with other progressive life limiting illnesses, promoting policy advocating a population based approach to palliative care delivery\(^{(31, 36)}\).

Another barrier to effective general practitioners’ engaging in palliative care is their sporadic palliative patient load, which makes it difficult to remain abreast of the rapidly expanding palliative care knowledge base\(^{(30, 31, 37)}\). However, population ageing, increased incidence of chronic and complex diseases, combined with the acceptance that palliative care is indicate for people with non-malignant disease, suggests that the demands on the general practitioner to provide palliative care will continue to expand\(^{(31)}\).

Few general practitioners have undertaken any formal palliative care training, with many medical curricula in Australia and internationally responding to this deficit\(^{(31)}\). However, ensuring general practitioners have adequate palliative care training presents many challenges\(^{(38, 39)}\). This makes exploring general practitioners’ palliative care educational needs a priority\(^{(37, 40, 41)}\). Previous research has identified that general practitioners perceive that they have had inadequate palliative care training\(^{(42)}\), particularly regarding the management of psychosocial issues\(^{(43)}\). Despite this limited training, general practitioners employ similar treatment strategies to those of specialist palliative care providers\(^{(37)}\). The needs of general practitioners, attitudes and experiences of general practitioners caring for dying patients in the community\(^{(44-48)}\), and patients’ and general practitioners’ perceptions of good end-of-life care\(^{(49)}\) have also been investigated.

In Australia’s system of universal health care coverage, the general practitioner plays a key role in providing effective, timely and appropriate palliative care to older people in aged care.
Within the community there is an expectation that general practitioners will have the prerequisite medical competencies, attitudes and practice arrangements required to provide residents with appropriate medical care, including palliative care\(^{32}\). Despite the general practitioners being integral to the delivery of a palliative approach in residential aged care, scant attention has been paid to the perceptions of general practitioner providing palliative care in this setting or their capacity to adopt and deliver a palliative approach.

### 6.6 Study F: The views of the general practitioner

In an attempt to gain a greater understanding of the impact of the intervention and to determine general practitioners’ views regarding the delivery of a palliative approach, a series of focus groups were conducted mid-way through the R-PAC Project in mid-2005.

#### 6.6.1 Aim

This exploratory study investigates general practitioners’ perceptions and beliefs about providing palliative care to older persons in residential aged care and their capacity to deliver a palliative approach.

#### 6.6.2 Design

A focus group design was implemented during the second phase of the action research process in August 2005. The needs assessment findings along with key informant interviews guided the question route for this study, which was developed to explore the general practitioners’ perspective of providing palliative care in residential aged care (Table 6-2).

#### 6.6.3 Participants

Forty general practitioners from eleven general practices located in Coffs Harbour were invited to participate in a focus group facilitated by an independent academic general practitioner. Every endeavour was made to schedule the focus groups at locations and times to suit general practitioners’ heavy workloads. A week prior to the scheduled focus group dates, a reminder call was made by the researcher. All participants gave freely of their time and no remuneration was provided.
A convenience sample of thirteen general practitioners from seven separate practices attended one of three focus group interviews conducted in August 2005. All of the participants knew one another and were actively involved in providing medical care to residents and home based palliative care patients\(^{(50)}\). Participants were not asked to provide any demographic details or additional details related to their length of time in general practice, previous palliative care experience, or number of their patients residing in residential aged care or receiving palliative care.

**Table 6-2: Focus group question route - general practitioners**

<table>
<thead>
<tr>
<th>Question route</th>
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<tbody>
<tr>
<td>What does the term ‘a palliative approach ‘mean to you as a general practitioner?</td>
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<tr>
<td>What are the barriers to delivering a palliative approach within local residential aged care facilities?</td>
</tr>
<tr>
<td>What are the barriers to providing end-of-life care in local residential aged care facilities?</td>
</tr>
<tr>
<td>Are there any things that would facilitate or enhance your ability to deliver a palliative approach within local residential aged care facilities?</td>
</tr>
<tr>
<td>Are there any things that would facilitate or enhance your ability to provide end-of-life care in local Residential Aged Care facilities?</td>
</tr>
<tr>
<td>Are there any other issues that you wish to discuss or comments you would like to make?</td>
</tr>
</tbody>
</table>

### 6.6.4 Data collection and analysis

Data collection and analysis were undertaken concurrently as reflexive activities, following the thematic content analysis framework described in Chapter Three\(^{(14)}\). An academic general practitioner moderated each focus group, while the researcher acted as an assistant\(^{(14)}\). It was considered that the use of a general practitioner moderator would assist participants’ comfort in discussing and disclosing information. Following each of the focus groups, the researchers met for an initial analysis session to reflect on group interactions, in particular identifying and noting non-verbal clues, endorsing values, opinions and beliefs and to capture their initial thoughts\(^{(15)}\). These sessions assisted in identifying and reaching consensus on recurring patterns and common themes, while the transcripts allowed for further revision, grouping and
reduction, with the final category coding of the broad analytic themes being verified with study participants\(^{(14)}\).

### 6.6.5 Findings

The participants’ perceptions about the provision of palliative care in aged care are described in the four key themes that emerged from the data: (1) Uncertainty about a palliative approach, (2) Need to re-orientate providers, (3) The challenges of managing third parties, and (4) Making it work and moving forward\(^{(2)}\).

**Uncertainty about a palliative approach**

Data revealed that there was wide variation in participant’s awareness and understanding and the concept of a palliative approach, with some participants having an integrated and inclusive perspective: ‘Improving the person’s quality of life for the time that the person has (left). That there is a focus on comfort … (it’s) not about prolonging life’ (general practitioner 9). Other participants readily acknowledged that palliative care was not merely limited to terminal care, but was care that often went on for an extended period of time: ‘There are often patients who go under the palliative umbrella for a long period of time, whereas end-of-life care is for a much shorter period of time’ (general practitioner 8). Yet, these views didn’t dominate as some participants struggled to determine whether palliative care was indeed applicable to people with non-malignant diseases: ‘When you use the term ‘palliative care’ I think we have moved away from just cancer patients’ (general practitioner 6). There was also uncertainty about whether palliative care was indicated for people with advanced dementia: ‘Is advanced dementia a palliative care situation?’ (general practitioner 10). There was uncertainty for some participants that palliative care was indicated for people with non-malignant disease, while a palliative approach was an emerging concept.

**Reorientating providers**

Overall, these participants saw that providing medical care to residents was their responsibility and an integral part of their practice, and expressed a genuine personal commitment to care for residents\(^{(2)}\). For many, the transition of their patients into residential care was facilitated by an established relationship with an associated sense of loyalty and a commitment to ensure that they received appropriate care, which endured in the absence of any financial incentives: ‘You wouldn’t do it for money…you do it more for love…I guess I
have a soft touch for the oldies and get fairly hostile when I see them being turfed to one side ... that's what really drives me’ (general practitioner 1). These participants were committed to providing ongoing medical care to older people in aged care and expressed frustration that more of their colleagues were not as actively involved: ‘We are the converted...the challenge is to mobilise the non-converted’ (general practitioner 7); and another comment, ‘From our surgery’s point of view there aren’t barriers to delivering a palliative approach...we attend every week and go regularly...but to get some of the other doctors to go there (residential aged care) you would need a crowbar’ (general practitioner 11). It was suggested that significant financial reimbursement and other incentives would be required to avert the current trend of general practitioners ceasing to provide care in this setting: ‘Unfortunately without a significant injection of cash nothing is going to shift that curve of those who provide and those who don’t provide(care)’ (general practitioner 12).

Participants described the difficulties they experienced trying to use the reimbursement items that have recently been introduced to remunerate general practitioner participation in care planning and case conferences\(^{(45, 46)}\): ‘...tried it for a while (using Enhanced Primary Care items), but I couldn’t make it happen and I just went back to my old ways’ (general practitioner 1). Consequently for many participants it was easier to continue to plan residents’ care in an ad hoc manner: ‘...spontaneous meeting...we do it informally’ (general practitioner 13). Participants suggested that heavy workloads ensured that many general practitioners were unable to visit residents until after-hours, including weekends\(^{(2)}\). Previous research has noted that there are greater time demands on rural general practitioners as they tend to have heavier workloads, care for more complex patients, provide a larger range and breadth of services and deliver more after-hours care than their urban counterparts\(^{(51, 52)}\). These factors all act to limit general practitioners’ availability to deliver medical care to the aged care sector. Participants perceived only being able to visit aged care after surgery hours was problematic as the senior nurses were rarely on duty after-hours. The lack of after-hours access to senior nurses effectively limited the general practitioner’s ability to discuss residents’ care with appropriate personnel: ‘... difficult after-hours because the regular staff aren’t there’ (general practitioner 13); and ‘... have different staff on the weekend....harder on the weekends...the staff don’t always know’ (general practitioner 1).

Some participants described how they often developed a degree of attachment to residents, particularly those they had known over an extended period of time\(^{(2)}\). It has been previously noted that many general practitioners feel a sense of loss and sometimes guilt over the death
of a well known patient and often need to have an opportunity to express this emotion\(^{(53)}\). Participants acknowledged that an enduring relationship with a patient had the potential to impact on their clinical objectivity. They described how if they were focused on restoring the resident to good health that they often failed to identify their actual palliative care needs. In this situation participants endeavoured to make a conscious effort to change the focus of care:

‘Sometimes I think I am the barrier… as when you get attached you keep on trying to get them better…you have to have a mind switch so that you know that isn’t appropriate anymore’ (general practitioner 4). The challenges associated with reorientating care reflects general practitioners’ medical bio-medical education, which is grounded in returning the person to good health\(^{(53)}\).

Participants suggested that palliative care education particularly in the area of dementia care was needed for both aged care nurses and general practitioner: ‘Education is needed for both staff (general practitioner and nurses)...there is a need for more dementia education’ (general practitioner 11). Participants also expressed concern that aged care nurses still lacked adequate pain management competencies and on-going education was needed: ‘…education for nursing staff… not giving them enough (analgesia)...need to consider comfort. (Nurses) Need to know how to step up medications’ (general practitioner 13). Participants expressed that education was required to re-orientate health care providers and further promote the delivery of a palliative approach.

**The challenges of managing third parties**

The data revealed that, for these participants, one of the greatest challenges in providing care in the aged care setting was managing various third parties, including families, nurses and the system\(^{(2)}\). Dealing with the emotions, values and beliefs of families in a time of crisis was identified as a considerable challenge: ‘It is only when we deal with families that we run into problems’ (general practitioner 6). Participants revealed that engaging the family in a collaborative decision making process was required to minimise conflict and communication difficulties, clarify their expectations and to establish the goals of care: ‘I make it my priority to meet them (family)...need to meet with them to determine their expectations...’ (general practitioner 12). Participants acknowledged that achieving consensus within a family was often a difficult and time consuming process, which made the care planning more complex: ‘Difficult when there is no unified stance to care within a family...brother and sister have different views as to what will be best for the patient...’ (general practitioner 4). In this context, meeting with the family, at the earliest opportunity was seen as being critical to
resolve differences of opinion and determine the goals of care: ‘Families are OK...as long as you get them in and have a chat’ (general practitioner 11); and ‘When we talk to families we need to map out the goals of care’ (general practitioner 9).

Overall the data revealed that these participants had respect for aged care nurses: ‘Residential aged care nurses are pretty good’ (general practitioner 1). Participants’ visits to aged care facilities provided them with an opportunity to establish rapport and trust with aged care personnel. Regular visits also allowed the general practitioner to develop a profile of the competencies of individual nurses and for the nurses to feel confident about working with the general practitioner. Establishing this type of working relationship was important to the participants as made it easier for them to deliver care: ‘...knowing the staff. It takes time to know the staff... some are a bit more capable than others, some trust your judgment’ (general practitioner 13). There was a perception among participants that aged care nurses were more comfortable and confident about managing a resident’s end-of-life care and there was a greater commitment not to transfer residents to hospital when they are dying: ‘...they (nurses) are getting much better at it [palliative care] over the past 12 months...we try and be more supportive....we are committed to keeping them in the nursing home’ (general practitioner 12). Several of the participants commented favourably on the link nurse role and valued this recently established in-house palliative care nursing resource(1): ‘... you get to know the staff, who is the link nurse.... .... It would be helpful to have these link nurses in other nursing homes’ (general practitioner 5).

Despite these positive trends, it was perceived that some aged care nurses still had inadequate symptom assessment skills. The assessment and management of residents’ pain was made more difficult if the information provided by nurses wasn’t based on sound clinical assessment: ‘...they (aged care nurses) don’t use the tools to let you know (clinical changes)’ (general practitioner 12); and ‘...phone and say that they are dying (resident) and need a morphine order...jump from nothing to morphine’ (general practitioner 4). Inadequate clinical information only added to the challenges and frustrations these participants experienced in servicing residential aged care. Participants suggested that encouraging and supporting nurses to use pain assessment tools was one strategy that could help to shape the reporting of clinical information is an objective and meaningful manner: ‘...sometimes they (nurses) say the person is in pain...I say let’s do a pain chart...I get them to use the tools...the simpler the better, one page tools are the best’ (general practitioner 13).
Study participants also expressed frustration in dealing with and managing the complex range of systems that govern the provision of care in aged care facilities. It was suggested that many of the administrative changes that had occurred in Australia since the introduction of the 1997 Aged Care Reform package had detracted from the providing of care for the resident and in the process had eroded the public’s trust in care delivery: ‘All much easier until 10 years ago...the trust of the public is damaged...the care of the resident has deteriorated...reams of meaningless notes...no one reads the notes’ (general practitioner 11). These changes occurred at a time when residents with higher levels of disability and disease were being admitted to aged care requiring greater nursing and medical input. Despite these escalating care needs, providers were increasingly caught up in onerous administrative duties which was perceived to detract them from the provision of clinical care: ‘The government needs to recognise that more and more older people are coming into the market ...we need nurses to get back to nursing and stop writing notes...and general practitioners need to take responsibility...’ (general practitioner 10). The increasing administrative burden on aged care nurses acts to limit the time available for care delivery which is thought to contribute to sub-optimal symptom management. General practitioners perceived that they are better off only seeing patients in the surgery as they are poorly renumerated for their aged care visits, are not paid for travelling time or for the administrative task associated with delivering medical care in this setting.

In addition, these participants suggested that it was challenging managing the care needs of deteriorating and dying residents in low care, particularly after-hours when the facility was staffed by unregulated workers supported by an on-call registered nurse: ‘...apart from within the hostel setting, after-hours ...because the regular staff aren’t there’ (general practitioner 13); and ‘...it just doesn’t work in a hostel setting ...especially towards the end-of-life’ (general practitioner 11). Participants described that the absence of appropriate equipment in aged care facilities often prompted a dying resident to be inappropriately transferred to hospital: ‘...if it gets too high tech they [aged care staff] flick them [residents] to hospital. They need to have easy access to equipment’ (general practitioner 7).

Making it work and moving forward

There was wide variability in the ways in which participants dealt with the unrelenting and often daily requests from residential aged care facilities. Some participants had developed individual systems to streamline and co-ordinate the delivery of care to older people in residential aged care facilities by allocating specific visiting times: ‘I am fairly
proactive….spend one day a week just doing home visits, including visits to Residential Aged Care Facilities’ (general practitioner 4). Another practice had assigned specific doctors to manage the medical care of all practice residents in specific facilities: ‘…we have recently changed… each doctor took a certain aged care facility…each of us now has a certain number(of residents)...I like this system ... it works well’ (general practitioner 5). Other strategies related to routinely reviewing medication orders and documenting ‘do not transfer to hospital orders’ for residents where transfer was not appropriate: ‘I don’t have a problem with my medication charts as I check them every time I go the facility’ (general practitioner 4); and ‘ …written order than no one is to be transferred to hospital’ (general practitioner 12). Having these systems in place gave some participants a sense of control over their workload and helped to reduce their personal frustration. This was in stark contrast to other participants who had few systems in place to manage the demands from aged care and just reacted to the myriad of requests on an ad hoc basis, which is best typified by this response: ‘I just do it when I have to’ (general practitioner 7). The participants without any evidence of systems almost seemed overwhelmed and powerless to initiate change to streamline these demands. Despite these wide variations in practice, all participants unanimously agreed with the need to implement more appropriate systems to more effectively manage these demands and to facilitate enhanced care delivery.

Participants suggested that creating regular in-house meeting to discuss and systematically plan all residents’ care needs was indicated: ‘The gold standard would be weekly team meetings…there is a need for regular review…the local (Aged Care Facilities) has a weekly meeting, need to have (general practitioner) input into it’ (general practitioner 11). For these in-house care planning meetings to be of real value, they needed to extend beyond the aged care personnel and include all other relevant health care providers and be truly multidisciplinary: ‘If the meetings involved others we would be interested …meetings have appeal if they involved others. Opportunity to establish the goals of care and to develop a treatment and care plan, …need to try and keep it as low tech as possible…’(general practitioner 1). This also offered an opportunity to seek input from specialist teams to assist with the management of residents’ complex care needs: ‘I think it is great getting palliative care involved…they have practical ideas of how to manage care’ (general practitioner 2). As general practitioners need timely access to specialist palliative care providers to optimise their patients care(31), the specialists teams’ input into this meeting would help enhance care delivery.
Participants agreed that establishing regular multidisciplinary case conferences or team meetings would also provide a forum for systematically exploring issues related to advance care planning. These participants were enthusiastic about the concept of advance care planning and believed that engaging in this process would aid communication with families and nurses about the residents’ desired level of intervention: ‘Advance care planning ....that’s what I think would help... it will also help communicate to aged care nurses...’ (general practitioner 4). While some participants felt that advance care planning provided a useful framework to guide difficult end-of-life discussions and assisted in defining the parameters of care and minimise conflict, others acknowledged its limitations: ‘In real life Advance Care Plans (Planning) are only guidelines...’ (general practitioner 6).

Participants suggested that the medical care of dying residents could be more effectively managed by using tools such as an end-of-life integrated care clinical pathway\(^{(56)}\): ‘The use of an end-of-life care pathway is most suitable for use in residential aged care facilities’ (general practitioner 11); and ‘The end-of-life care pathway is excellent...if it’s on there it should be done...’ (general practitioner 12). Some participants also indicated that discussing residents’ end-of-life care needs is best done within a multidisciplinary team setting, involving aged care personnel and the family.

While remote access to the residents’ medical records was seen as having the potential to create greater efficiencies, streamlining processes, improving communication and adopting technological solutions would also ultimately save the general practitioner time: ‘Computer technology will enable me to update all of the medications there (aged care facilities)....instead of coming away with all scraps of paper that I work on for the next week or so, .....it’s all done there. It will save time and ....enhances communication. It will stop this forest of faxes’ (general practitioner 1).

### 6.6.6 Discussion: Implications for general practice

In Australia, the general practitioner has a critical role in working collaboratively with other health care providers to determine the goals of care for people with complex care needs, including those in residential aged care\(^{(57, 58)}\). Within this system there is also an increasing emphasis on multidisciplinary care to promote better health outcomes\(^{(32, 59)}\). The general practitioner is responsible for providing the resident’s medical care and this medical input is integral to delivering a palliative approach\(^{(31)}\). This study found that there was considerable variation in general practitioners’ awareness of a palliative approach and some uncertainty...
about its applicability in aged care, particularly for people with non-malignant conditions, which is of concern given the the burden of disability and deaths in this setting\(^{(59, 60)}\). These differing levels of understanding may in part be explained by the small number of palliative care patients actually cared for by general practitioners\(^{(48, 61)}\). In Australia, it is estimated that each general practitioner only provides end-of-life care for approximately five to seven patients per year, although this figure can vary widely\(^{(31, 37)}\). Clearly, this makes it challenging for general practitioners to maintain their palliative care competencies and remain abreast of emerging trends\(^{(45)}\), particularly given the increasing competing education demands across the spectrum of general practice\(^{(62)}\). At the time of this study, there had been no targeted general practitioner education about the release of the palliative approach guidelines, unlike that implemented for aged care management and nurses\(^{(63)}\). Few of the general practitioners involved in the focus groups were aware of this new paradigm.

In an environment of competing educational priorities, it is difficult for the average general practitioner with a small number of palliative care patients to keep up with palliative care’s rapidly expanding knowledge base\(^{(30, 62)}\). Importantly, the concept of a palliative approach is being acknowledged in targeted general practice publications, such as the recently updated Royal Australian College of General practitioners guidelines for the ‘Medical care of older persons in residential aged care’\(^{(32)}\). Publications such as this will assist in promoting greater general practitioner awareness of the need to re-orientate residents care from a ‘cure’ to ‘comfort’ focus, particularly in the last 6-12 months of life\(^{(32)}\). However, as education alone is not always translated into changed practices, a multi-level intervention framework comprised of educational, organisational support strategies aimed at increasing general practitioners’ palliative approach competencies is required to ensure that residents’ palliative care needs do not go unrecognized and untreated\(^{(18)}\).

Study findings suggest that a range of other supports are required to facilitate greater general practitioner involvement in the delivery of a palliative approach. Additional financial incentives and developing of multidisciplinary care models are required to secure ongoing general practitioner involvement in the aged care sector. For many general practitioners, their heavy practice workloads and time constraints\(^{(30, 31, 52)}\) help to ensure that they can only visit after-hours, when senior nurses are less likely to be on duty, which makes it difficult to create a collaborative approach to care\(^{(18, 64)}\). This situation can be further compounded by role delineation ambiguity between health care providers, a lack of understanding of a common philosophy of care, such as a palliative approach, and the lack of a common vocabulary\(^{(18, 64)}\).
CHAPTER SIX

GP & AGED CARE FOCUS GROUPS

All of these factors act as barriers to collaborative care planning and the delivery of a palliative approach.

This study confirms earlier observations that there is a wide variation in general practitioner involvement in residents’ care with some general practitioners maintaining an active and central role in care provision\(^{44, 46}\), while others are relinquishing their care responsibilities\(^{65}\). Increased regulation may in part explain the disparity in general practitioner involvement in the aged care sector\(^{31, 52}\). Unfortunately, when a single general practitioner relinquishes responsibility for a residents’ care, it places an additional burden on the diminishing number of general practitioner servicing local aged care facilities\(^{65}\) and also forces the resident and their family to establish a new relationship with another provider.

6.6.7 Limitations

It is not possible to generalise the findings of this study as the data were context-specific and obtained using convenience sampling. Recruiting general practitioners to participate in this study was challenging, with heavy workloads and time commitments cited as the reasons for non-participation. Therefore the size of the focus groups was much smaller than recommended\(^{3, 9}\). Further, the method of sampling may have recruited general practitioners who had a special interest in aged and palliative care issues and their views may not necessarily reflect those of non-participants. In spite of these limitations, this study addresses issues related to a single setting and identifies potential strategies that are likely to be applicable to other residential aged care settings in regional Australia. Of further importance is that these data provide insight into a range of opinions expressed by working general practitioners to enhance palliative care delivery in the aged care sector.

6.7 Integrating focus group findings: Discovering the common ground

The perspectives of the aged care providers’ and general practitioners’ focus groups are discussed individually as they were conducted as two separate studies\(^{1, 2}\). The reason for this was to allow the values and beliefs of these key groups to be freely disclosed within professional contexts. Following the analysis of the data sets, individual data were compared to elucidate common issues and concerns\(^{66}\), which are summarised in Figure 6-1. The common issues which emerged relate to the creation of multidisciplinary teams as a vehicle to enhance communication, collaboration and care planning.
6.7.1 Collaboration

It is encouraging that general practitioners and aged care personnel both aspire to be more proactive in the establishment of collaborative models of care that are multidisciplinary and seek the input of residents and their families\(^{(67)}\). Continuity of care depends on the capability of health care providers to create effective multidisciplinary teams at an interagency level\(^{(64)}\). Creating a new care team is particularly important as admission to an aged care facility is a sentinel event for the older person and their family\(^{(18, 68)}\). Admission to aged care usually heralds a transition from a dyadic relationship between the older person and their general practitioner, to the formation of a resident, health care provider and family triad\(^{(21)}\). Establishing effective relationships between these parties is critical given residents’ high levels of cognitive impairment, fragility and disability. However, this newly formed ‘caregiver coalition’ is rarely acknowledged nor are processes put in place to effectively managed these changed dynamics\(^{(21)}\). This takes on increasing importance given the high incidence of cognitive impairment amongst residents, which makes engaging the person responsible in care discussion critical to determining the goal of care, care collaboration and decision making\(^{(19, 69)}\). In NSW, the ‘person responsible’ is a legal term used to describe who
is responsible for making health related decisions for an individual with a decision making disability\(^{(70)}\).

The findings from both data sets suggest that negotiating and defining these care roles amongst the newly formed care team is unlikely to occur in the current care environment due to time constraints and the absence of processes to discuss and formalise residents’ care arrangements\(^{(1, 2)}\). Yet, mapping out these processes is required to prevent role confusion, minimise conflict\(^{(64)}\) and clarify decision making\(^{(21)}\). Determining which team member has the coordinating responsibility for management of the resident’s care will prevent further communication breakdowns\(^{(71)}\).

### 6.7.2 Communication

General practitioners and aged care nurses both acknowledged the numerous communication challenges they encountered in the residential aged care setting. For many general practitioners, the time consuming nature of providing care to older people in residential aged care is amplified by the challenges of communicating with other health care providers, residents and their families. Yet, previous research has identified that patients and carers value and place importance on their relationship with their primary care providers\(^{(31)}\). This relationship makes effective communication a key element of all care delivery. However, time demands and diminishing resources mean that general practitioners increasingly operate in an environment where they rarely get to meet face-to-face with aged care nurses to discuss residents’ care needs\(^{(64)}\). This lack of contact makes it difficult to create a collaborative approach to care, which can be compounded by role ambiguity, lack of a common philosophy of care and vocabulary\(^{(1, 64)}\). Aged care nurses feel frustrated about some general practitioners’ misconceptions of a palliative approach philosophy, which has the potential for causing conflict\(^{(1)}\). Field identified that mutual respect, sound communication and the adoption of a common language are critical elements for a team approach to palliative care delivery\(^{(44)}\). In addition, effective multidisciplinary networking is dependent upon health care providers having an a clear understanding of other’s roles and expertise\(^{(64)}\). It is reassuring that aged care nurses and care assistants felt more confident following the multifaceted intervention to engage residents and family in these discussions about goals of care. However, if these conversations occur in the absence of general practitioner input, they may inadvertently contribute to conflict and misunderstanding. Many of these identified
challenges could be resolved by creating a multidisciplinary forum to facilitate planning residents care in collaborative manner.

### 6.7.3 Multidisciplinary care planning

Multidisciplinary care emphasises the need for a team approach, involving all core disciplines integral to the provision of good palliative care, including general practice\(^{(72)}\). In the aged care setting the multidisciplinary team ought to consist of all relevant health care providers required to address the care needs of each resident and their family. It is likely to consist of a mix of aged care, health and social welfare disciplines\(^{(55)}\). Ideally, an individual multidisciplinary team is created for each resident in accordance with their needs. Engaging different health care providers requires that suitable processes are established to promote communication among team members regarding care planning and appropriate systems to ensure that all residents have access to relevant services\(^{(72)}\). A multidisciplinary approach facilitates the delivery of care in accordance with nationally agreed standards and ensures that residents and their families are actively involved in decisions about their care\(^{(72)}\).

Establishing regular multidisciplinary case conferences within residential aged care facilities offers the potential to create a forum where care delivery can be effectively negotiated. Multidisciplinary case conferences have the potential to facilitate: more systematic general practitioner input, clarify care roles and responsibilities, and actively engage the resident and their family in the care planning process. Creating a regular multidisciplinary forum in aged care facilities would assist in gaining consensus on the goals of care, collaboratively plan the resident’s care and promote the delivery of a palliative approach in a systematic manner. It could create a supportive learning environment where aged care personnel and general practitioners learn through actions, while identifying effective strategies to overcome clinical problems\(^{(73-75)}\).

Previous research has identified the challenges associated with the logistics of arranging case conferences and that many general practitioners are skeptical about the gains to be made using available reimbursement items\(^{(76-78)}\). These barriers need to be addressed so that processes are established to ensure multidisciplinary aged care case conferencing is time efficient, outcome driven, and involves all relevant providers. Aged care nurses are in a unique position of having intimate knowledge of the resident and their family and may be best suited to arranging the multidisciplinary case conference. The input of the general practitioner with their in-depth medical knowledge of the resident and understanding of their family is required.
for effective care delivery. This clinical knowledge makes active engagement of the general practitioner a critical element.

The shift toward multidisciplinary, collaborative practice will not occur in a vacuum and general practitioners and aged care nurses will require support, infrastructure and training. On the basis of our findings and others providing adequate reimbursement, clarifying of roles and promotion of systems and care models for promoting multidisciplinary practice are challenges that need to be addressed in the clinical, policy and education settings to promote the delivery of a palliative approach in residential aged care. Undoubtedly, this has implications not only for multidisciplinary practice but also professional education and model of care development.

6.8 Options to enhance the delivery of a palliative approach

Informed by the views of aged care workers and general practitioners, the Critical Reference Group considered that there was scope to align a number of disparate but linked processes operating in the aged and primary care settings to achieve greater efficiencies in residents’ care planning and delivery (Figure 6-2). This framework is based on linking four discrete policy initiatives:

1. **Reimbursement**: There are opportunities to fund general practitioners’ engagement in the resident’s care planning by utilising a range of Medicare case conferencing items, which to date have been underutilised\(^{76, 79, 80}\). In addition, ensuring that all newly admitted residents had a comprehensive medical assessment completed within 6 to 8 weeks of admissions is essential for collaborative care delivery.

2. **Resident Classification Scale**: Ensure that all relevant health care providers have input into reviewing all residents’ care needs in accordance with the ‘Resident Classification System’\(^{81}\). This system mandates that residents’ care needs are reviewed annually or whenever there is a significant change in their clinical status\(^{82}\). Despite the complexity of residents’ care needs, the majority of these reviews are carried out independently by aged care nurses\(^{31}\).

3. **Palliative approach guidelines**: Promoting the delivery of a palliative approach in aged care in accordance with the evidence based guidelines\(^{59}\).
4. Multidisciplinary care: Arranging a multidisciplinary case conference at critical points in the resident’s trajectory may help to maximise general practitioner input\(^{(61)}\) and plan more effective care. These critical points are when residents are: admitted to residential aged care facilities, discharged from acute care, and experiences a change in their clinical status. Establishing policy that ensured that multidisciplinary care conference occurred at these critical points would enable the multidisciplinary team to better determine whether the resident requires ongoing maintenance of a palliative approach, specialist team input or end-of-life care.

**Figure 6-2:** Integrating multidisciplinary care planning into existing aged care processes

Establishing an in-house team and linking multidisciplinary care planning to current funding and reporting processes provides a unique opportunity to further explore enhancing the delivery of a palliative approach in residential aged care. Capitalising on the continuous quality improvement cycle and education mechanisms that already exist within the aged care sector will provide additional synergy for change. The Critical Reference Group acknowledged that, in considering establishing of a multidisciplinary case conferencing
within residential aged care, the interdependence of this forum on other parts of the organisation needs to be recognised and a systematic approach applied to its development to promote effective sharing of knowledge across clinical boundaries\(^{(83)}\). This proposal requires further exploration with general practitioners, aged care nurses, residents and families along with systematic evaluation. In addition, identifying strategies to ensure that residents and their families have an understanding of a palliative approach requires further thought. Exploring the perceptions and experiences of residents and their families are important consideration.

### 6.9 Using the data to move on

Data revealed that the multifaceted intervention was an enabling factor in increasing aged care nurses’ and care assistants’ palliative care competencies and confidence, having a positive impact on increasing the adoption of a palliative approach. As the data reported is based on self reports of outcomes and change, the Critical Reference Group considered that the next step was to determine the degree to which a palliative approach has actually been translated into practice. Consequently, measuring the degree to which the palliative approach guidelines were impacting on providing residents’ care was considered to be an important step towards identifying gaps in care provision and developing additional targeted interventions to further embed a palliative approach to care.

In the following chapter the impact of the intervention is assessed in a series of quantitative studies including the impact on palliative care competencies and levels of confidence of aged care personnel.
6.10 Reference list


5. van Eyk, H., & Baum, F. (2003). Evaluating health system change - Using focus groups and a developing discussion paper to compile the "voices from the field". *Qualitative Health Research*, 13(2), 281-6.


CHAPTER SIX


Chapter 7.

Measuring the Impact of the R-PAC Project’s Action
‘A little knowledge that acts is worth infinitely more than much knowledge that is idle’  
Kahlil Gibran

7.1 Introduction

The previous chapter has described the opinions of residential aged care personnel and general practitioners in relation to the R-PAC Project’s multifaceted intervention and importantly derived their opinions regarding the next phase of the action research process. The data derived from the focus group studies (Studies E and F) showed that there was a perception among aged care personnel and general practitioners that a positive change in the delivery of a palliative approach to care had occurred. Of note, aged care personnel reported having more confidence in their palliative care competencies, feeling more comfortable about discussing dying and negotiating residents’ care needs and possessed an increased understanding of a palliative approach. Encouragingly, the general practitioner data revealed that they also had noticed a positive difference in aged care nurses’ and care assistants’ skills and commitment towards caring for dying residents. General practitioners also reported that local aged care facilities were less likely to refer residents to the acute care setting for end-of-life care.

Encouraged by these results the Critical Reference Group was keen to determine whether the changes perceived by participants had actually increased the palliative care competencies of aged care personnel and, particularly, whether these had been translated into better palliative care delivery for residents. In an effort to answer these questions a post-test evaluation study was undertaken. This involved a post-test survey\(^{(1)}\) (Study G) to assess residential aged care personnel’s views and attitudes towards a palliative approach and post-test chart audit of indicators of a palliative approach to care based on evidence based guidelines\(^{(2, 3)}\) (Study H). Methodological and ethical issues as well as the properties of the audit tool and survey instrument are described in Chapter Three. The comparison between the Time 1 (pre-test) and Time 2 (post-test) data sets are discussed in this chapter.

7.2 Study G: Survey of age care personnel’s palliative care competencies, attitudes and values

Delivering best practice care is dependant upon reducing variations in clinical practice\(^{(4-6)}\). The R-PAC Project worked collaboratively with aged care providers in promoting a palliative approach for older people in nine aged care facilities through the developing of a multifaceted
intervention, involving a tailored learning and development strategy, promoting the adoption of evidence based guidelines, use of empowerment strategies and networking opportunities. This multifaceted intervention aimed to enhance aged care nurses’ and care assistants’ clinical decision making skills by increasing their palliative care knowledge and skills. The survey\(^{(1)}\) was re-administered to aged care providers during the fourth phase of the R-PAC Project’s action research process to assess changes in their palliative care knowledge and skills.

### 7.2.1 Aims

As described in Chapter Three, the survey instrument ‘Tool 2.1: Palliative care providers’ views and attitudes’\(^{(1)}\) (Appendix 6) was administered to aged care nurses and care assistants at baseline (Time 1)\(^{(7)}\) and following the implementation of the multifaceted intervention (Time 2). This pre-test – post-test study aimed to assess any changes in the views and attitudes of aged care personnel towards palliative care and their self-reported palliative care learning needs.

### 7.2.2 Sample

The survey was administered by the researcher in feedback sessions following the implementation of the multifaceted intervention. A total of 222 aged care nurses and care assistants completed the Time 1 (pre-test) survey, while 183 completed the Time 2 (post-test) survey. As well as considering the impact of the intervention on a population basis, three discrete groups were of particular interest, registered nurses (RN), enrolled nurses (EN) and care assistants (CA) because of their scope of practice and unique learning needs\(^{(8)}\).

### 7.2.3 Data analysis

As previously discussed in Chapter Three the data were entered into the Statistical Package for Social Science (SPSS) Version 14.0 to derive frequency estimates. Percentages in the tables not adding to 100 indicate missing values. As previously described in Chapter Four, the results related to ‘Views about palliative care’ have been aggregated into two categories: Group 1 (G1) with values less than 50% taken to indicate higher levels of perceived need for further support and supervision, and Group 2 (G2) with values greater than 50% taken to indicate lower levels of perceived need for further support and supervision (G2). These values reflect significant groupings in the data.
The independent sample t-test has been used to compare the mean scores of the aged care providers who completed the survey at Time 1 and Time 2, \( p<0.05 \) being used as the criterion for statistical significance\(^9\). The independent samples t-test is used to compare the mean score, on some continuous variable, for two different groups of subjects. This test determines the probability that the two sets of scores came from the same population. In applying this test, the following assumptions have been made about these two independent groups: that sampling techniques derived an uncontrolled random selection of participants; that each respondent completed the survey independently; and the populations from which the samples were taken were normally distributed\(^9\). The Levene test has been used to determine whether the Time 1 and Time 2 groups are obtained from populations of equal variances\(^9\).

7.2.4 Results

Key study findings are reported in Tables 7-1 to 7-6. Although, the Time 1 findings have been reported in Chapter 4, these will be repeated in this chapter in a pre-test format to enable the reader to assess and observe the impact of the action research process.

A total of 183 completed surveys were returned at Time 2, representing a response rate of 81%. The Time 2 sample was composed of registered nurses \((n=38)\), enrolled nurses \((n=28)\) and care assistants \((n=116)\) employed by local residential aged care facilities in Coffs Harbour. This survey sample represents 40\% \((n=460)\) of the total population of the local aged care workforce employed during Phase Four of the R-PAC Project.

Demographic data and professional characteristics

Table 7-1 summaries the demographic details of the aged care staff at Time 1 and Time 2. The mean age of the sample has increased from 46 [\(SD \pm 9\)] at Time 1 to 47.5 [\(SD \pm 8.86\)] years at Time 2. Few participants identified as being Aboriginal or Torres Straight Islander peoples or from culturally and linguistically diverse backgrounds. There are differences between the two groups with fewer registered nurses completing the survey at Time 2 \([n=38 (21\%) \text{ versus } n=62 (28\%)]\). A larger number of participants reported having completed a palliative care course at Time 2 (Figure 7-1). There are statistical differences in the number of aged care personnel who reported having completed a short courses leading to a specialist qualification, on the job training and having no palliative care training.
Table 7-1: Demographic details aged care personnel Time 1 and 2

<table>
<thead>
<tr>
<th>Demographic details</th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>(%)</td>
</tr>
<tr>
<td>(222)</td>
<td>(100)</td>
<td>(183)</td>
</tr>
<tr>
<td>Age mean (SD) years</td>
<td>45.73 years (± 9.04)</td>
<td>47.51 years (± 8.86)</td>
</tr>
<tr>
<td>Male</td>
<td>24</td>
<td>(11)</td>
</tr>
<tr>
<td>Female</td>
<td>195</td>
<td>(88)</td>
</tr>
<tr>
<td>Aboriginal or Torres Straight Islander identity</td>
<td>4</td>
<td>(2)</td>
</tr>
<tr>
<td>Other cultural or ethnic identity</td>
<td>9</td>
<td>(4)</td>
</tr>
<tr>
<td>Registered Nurses</td>
<td>62</td>
<td>(28)</td>
</tr>
<tr>
<td>Enrolled Nurses</td>
<td>38</td>
<td>(16)</td>
</tr>
<tr>
<td>Care Assistants</td>
<td>111</td>
<td>(50)</td>
</tr>
</tbody>
</table>

Figure 7-1: Difference in palliative care education at Time 1 and 2 by discipline
Degree of confidence with patient, family interactions and patient management

Figure 7-2 and 7-3 depicts the percentage differences from Time 1 and 2 in aged care personnel’s levels of independence and dependence to discuss palliative care issues with residents and their families and manage a range of common palliative care symptoms. All disciplines reported having higher levels of independence to manage these issues at Time 2 compared to Time 1, except for registered nurses who reported lower levels of independence at the end of the R-PAC Project, related to: ‘informing people of the support services’ (Question 3), and ‘reacting to and coping with reports of constipation’ (Question 11). A significant difference between the Time 1 and Time 2 groups in terms of level of independence was observed, relating to: ‘informing people of the support services’ (Question 3); discussing different environmental options (Question 4), discussing patients’ wishes for after their death (Question 5); answering queries about the effects of certain medications (Question 6); reacting to reports of pain from the patient (Question 7); reacting to and coping with terminal delirium (question 8); reacting to and coping with terminal dyspnoea (Question 9); and reacting to and coping with limited patient decision making capacity (Question 12) (Table 7-2).

Views about death and dying

Participants’ views about death at Time 1 and 2 are summaries in Table 7-3. Differences in the mean at Time 1 and 2 are noted for the following views: the use of strong pain medication can cause the person to stop breathing (View 3); and I am not comfortable talking to families about death (View 5); both were found to be statistically significant.

Attitudes towards palliative care

Table 7-4 summarises participant’s attitudes towards palliative care at Time 1 and 2. Differences in the mean for the two groups are reported for the following attitudes: addiction to morphine is not a serious issue given that terminally ill patients have a short time to live (Attitude 7); opening discussions of end-of-life care should be deferred until there is no further curative treatment available (Attitude 8); estimation of pain by a MD or RN is a more valid measure of pain than patient self report (Attitude 9) and patients have the right to determine their own degree of psychosocial intervention (Attitude 11).
Figure 7-2: Differences in level of independence to manage symptoms between Time 1 and 2

Figure 7-3: Differences in level of dependence to manage symptoms between Time 1 and 2
**Table 7-2:** Degree of confidence with patient/family interactions and management Time 1 and 2

<table>
<thead>
<tr>
<th>Confidence to answer these 12 questions</th>
<th>Time 1 (n=222) m ± SD</th>
<th>Time 2 (n=183) m ± SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Answering patients questions about the dying process</td>
<td>2.50 ± 1.07</td>
<td>3.16±2.34</td>
<td>-3.70</td>
<td>0.00</td>
</tr>
<tr>
<td>2. Supporting the family when they become upset</td>
<td>3.12 ± 0.89</td>
<td>3.57±2.52</td>
<td>-2.49</td>
<td>0.01</td>
</tr>
<tr>
<td>3. Informing people of the support services available</td>
<td>2.23 ± 1.04</td>
<td>2.74±0.91</td>
<td>-5.27</td>
<td>0.00</td>
</tr>
<tr>
<td>4. Discussing different environmental options</td>
<td>2.45 ± 1.09</td>
<td>3.01 ± 0.99</td>
<td>-5.38</td>
<td>0.00</td>
</tr>
<tr>
<td>5. Discussing patients wishes after their death</td>
<td>2.70 ± 1.09</td>
<td>3.10 ± 0.90</td>
<td>-4.06</td>
<td>0.00</td>
</tr>
<tr>
<td>6. Answering queries about the effects of certain medications</td>
<td>1.97 ± 1.02</td>
<td>2.33 ± 1.03</td>
<td>-3.53</td>
<td>0.00</td>
</tr>
<tr>
<td>7. Reacting and coping with pain</td>
<td>3.00 ± 0.96</td>
<td>3.22 ± 0.82</td>
<td>-2.50</td>
<td>0.01</td>
</tr>
<tr>
<td>8. Reacting and coping with terminal delirium</td>
<td>2.67 ± 1.02</td>
<td>2.99 ± 0.92</td>
<td>-3.36</td>
<td>0.00</td>
</tr>
<tr>
<td>9. Reacting and coping with terminal dyspnoea</td>
<td>2.76 ± 1.01</td>
<td>2.99 ± 0.84</td>
<td>-2.53</td>
<td>0.01</td>
</tr>
<tr>
<td>10. Reacting and coping with nausea and vomiting</td>
<td>3.16 ± 0.92</td>
<td>3.22 ± 0.82</td>
<td>-0.71</td>
<td>0.50</td>
</tr>
<tr>
<td>11. Reacting and coping with constipation</td>
<td>3.19 ± 0.86</td>
<td>3.34 ± 0.84</td>
<td>-1.70</td>
<td>0.09</td>
</tr>
<tr>
<td>12. Reacting and coping with limited patient decision making capacity</td>
<td>2.83 ± 0.94</td>
<td>3.14 ± 0.80</td>
<td>-3.51</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**Possible score range**

Basically dependent: 1 = needs further basic instruction; or 2 = confident to perform with close supervision/coaching.

Basically independent: 3= perform with minimal supervision/consultation; or 4= perform independently.
### Table 7-3: Aged care personnel’s views towards death and dying Time 1 and 2

<table>
<thead>
<tr>
<th>Views towards death and dying</th>
<th>Time 1</th>
<th>Time 2</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=222)</td>
<td>(n=183)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>m ± SD</td>
<td>m ± SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. The end of life is a time of great suffering</td>
<td>3.83 ± 1.02</td>
<td>3.84 ± 1.12</td>
<td>-0.07</td>
<td>0.95</td>
</tr>
<tr>
<td>2. Little can be done to help someone achieve a sense of peace at the end of life</td>
<td>4.45 ± 0.66</td>
<td>4.55 ± 0.68</td>
<td>-1.53</td>
<td>0.13</td>
</tr>
<tr>
<td>3. The use of strong pain medication can cause the person to stop breathing</td>
<td>3.66 ± 0.90</td>
<td>3.99 ± 1.06</td>
<td>-3.40</td>
<td>0.00</td>
</tr>
<tr>
<td>4. I am not comfortable caring for a dying patient</td>
<td>4.52 ± 0.67</td>
<td>4.54 ± 0.72</td>
<td>-0.33</td>
<td>0.74</td>
</tr>
<tr>
<td>5. I am not comfortable talking to families about death</td>
<td>4.09 ± 0.92</td>
<td>4.29 ± 0.83</td>
<td>-2.32</td>
<td>0.02</td>
</tr>
<tr>
<td>6. When a patient dies I feel that something went wrong</td>
<td>4.50 ± 0.58</td>
<td>4.56 ± 0.68</td>
<td>-0.93</td>
<td>0.36</td>
</tr>
<tr>
<td>7. Feeding tubes should be used to prevent starvation at the end of life</td>
<td>4.05 ± 0.90</td>
<td>4.21 ± 0.88</td>
<td>-1.84</td>
<td>0.07</td>
</tr>
<tr>
<td>8. Nursing homes/hospitals are not good places to die</td>
<td>4.24 ± 0.85</td>
<td>4.39 ± 0.79</td>
<td>-1.82</td>
<td>0.07</td>
</tr>
<tr>
<td>9. Families have the right to refuse a medical treatment, even if that treatment prolongs life</td>
<td>2.11 ± 1.02</td>
<td>2.09 ± 1.06</td>
<td>0.20</td>
<td>0.84</td>
</tr>
<tr>
<td>10. Dying patients should be referred to a hospice or acute care</td>
<td>4.15 ± 0.87</td>
<td>4.30 ± 0.73</td>
<td>-1.86</td>
<td>0.06</td>
</tr>
</tbody>
</table>

**Possible score range:** 1 = Mostly Disagree, 2 = Unsure Mixed, 3= Mostly Agree
### Table 7-4: Aged care personnel’s attitudes towards palliative care Time 1 and 2

<table>
<thead>
<tr>
<th>Attitudes towards palliative care</th>
<th>Time 1 (n=222)</th>
<th>Time 2 (n=183)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pain at the end of life is an inevitable part of the dying process</td>
<td>4.11 ± 0.87</td>
<td>4.11 ± 0.89</td>
<td>0.38</td>
<td>0.97</td>
</tr>
<tr>
<td>2. Pain medication should be given as needed to terminally ill patients</td>
<td>1.58 ± 0.83</td>
<td>1.66 ± 1.02</td>
<td>-0.81</td>
<td>0.42</td>
</tr>
<tr>
<td>3. Spiritual care should include counselling the terminally ill patient</td>
<td>1.97 ± 0.94</td>
<td>2.14 ± 1.07</td>
<td>-1.63</td>
<td>0.11</td>
</tr>
<tr>
<td>4. I do not like talking about death and dying with patients</td>
<td>4.05 ± 0.80</td>
<td>4.04 ± 0.80</td>
<td>0.07</td>
<td>0.94</td>
</tr>
<tr>
<td>5. Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness</td>
<td>1.93 ± 1.13</td>
<td>1.86 ± 1.15</td>
<td>0.61</td>
<td>0.54</td>
</tr>
<tr>
<td>6. Patients should have the right to determine their own degree of medical intervention</td>
<td>1.60 ± 0.76</td>
<td>1.64 ± 0.83</td>
<td>-0.52</td>
<td>0.60</td>
</tr>
<tr>
<td>7. Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live</td>
<td>2.09 ± 1.09</td>
<td>1.84 ± 0.93</td>
<td>2.49</td>
<td>0.01</td>
</tr>
<tr>
<td>8. Opening discussions of end-of-life care should be deferred until there is no further effective curative treatment available</td>
<td>3.83 ± 0.98</td>
<td>4.07 ± 0.98</td>
<td>-2.37</td>
<td>0.02</td>
</tr>
<tr>
<td>9. Estimation of pain by an MD or RN is a more valid measure of pain than patient self-report</td>
<td>3.85 ± 0.96</td>
<td>4.10 ± 0.97</td>
<td>-2.63</td>
<td>0.01</td>
</tr>
<tr>
<td>10. Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition such as cancer</td>
<td>1.97 ± 0.96</td>
<td>1.84 ± 0.92</td>
<td>1.41</td>
<td>0.16</td>
</tr>
<tr>
<td>11. Patients have the right to determine their own degree of psychosocial intervention</td>
<td>2.04 ± 1.02</td>
<td>1.75 ± 0.70</td>
<td>3.23</td>
<td>0.00</td>
</tr>
<tr>
<td>12. The most appropriate person to make end-of-life decisions is the patient’s primary care provider</td>
<td>3.45 ± 1.04</td>
<td>3.35 ± 1.05</td>
<td>0.95</td>
<td>0.34</td>
</tr>
<tr>
<td>13. A patient should experience discomfort prior to receiving the next dose of pain medications</td>
<td>4.36 ± 0.84</td>
<td>4.36 ± 0.91</td>
<td>0.111</td>
<td>0.912</td>
</tr>
<tr>
<td>14. Patients should be maintained in a pain-free state</td>
<td>1.74 ± 0.95</td>
<td>1.66 ± 0.88</td>
<td>0.90</td>
<td>0.37</td>
</tr>
<tr>
<td>15. As a rule, terminally ill patients prefer not to talk about death and dying</td>
<td>3.67 ± 0.85</td>
<td>3.64 ± 0.93</td>
<td>0.25</td>
<td>0.80</td>
</tr>
</tbody>
</table>

**Possible score range:** 1 = Mostly Disagree, 2 = Unsure Mixed, 3= Mostly Agree
**Importance of issues associated with end-of-life care**

Figure 7-4 illustrates that there was little change in aged care providers ranking of issues associated with end of life care at Time 1 and 2 as being ‘being mostly important’. Differences in the mean of the two groups were only found for ‘uncertainty about what is best care’ (Table 7-5).

**Figure 7-4**: Percentage of aged care personnel who ranked these end-of-life issues at Time 1 and Time 2 as being ‘mostly important’
**Table 7-5:** Aged care personnel’s ranking of importance of end-of-life issues Time 1 and 2

<table>
<thead>
<tr>
<th>Importance of end-of-life issues</th>
<th>Time 1 (n=222)</th>
<th>Time 2 (n=183)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>m ± SD</td>
<td>m ± SD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Control of pain</td>
<td>1.11 ± 0.46</td>
<td>1.06 ± 0.24</td>
<td>1.38</td>
<td>0.17</td>
</tr>
<tr>
<td>2. Managing depression</td>
<td>1.33 ± 0.66</td>
<td>1.26 ± 0.46</td>
<td>1.23</td>
<td>0.22</td>
</tr>
<tr>
<td>3. Legal concerns</td>
<td>2.02 ± 1.07</td>
<td>1.89 ± 1.11</td>
<td>1.26</td>
<td>0.21</td>
</tr>
<tr>
<td>4. Ability to meet spiritual needs</td>
<td>1.44 ± 0.66</td>
<td>1.42 ± 0.65</td>
<td>0.39</td>
<td>0.69</td>
</tr>
<tr>
<td>5. The patient’s emotional needs</td>
<td>1.23 ± 0.54</td>
<td>1.20 ± 0.81</td>
<td>0.37</td>
<td>0.71</td>
</tr>
<tr>
<td>6. Communication with family</td>
<td>1.26 ± 0.55</td>
<td>1.21 ± 0.41</td>
<td>0.94</td>
<td>0.35</td>
</tr>
<tr>
<td>7. Communication with palliative care staff</td>
<td>1.37 ± 0.68</td>
<td>1.27 ± 0.57</td>
<td>1.56</td>
<td>0.12</td>
</tr>
<tr>
<td>8. Communication with doctors</td>
<td>1.45 ± 0.75</td>
<td>1.38 ± 0.72</td>
<td>0.92</td>
<td>0.36</td>
</tr>
<tr>
<td>10. Uncertainty about what is best care</td>
<td>2.10 ± 1.31</td>
<td>2.55 ± 1.69</td>
<td>-2.95</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**Possible score range:** 1= most important issue - 10= least important issue

**Palliative care education needs**

Table 7-6 describes the differences between Time 1 and Time 2 in respect of their future palliative care education needs, while in Figure 7-5 these changes are illustrated dynamically over the study period. For each discipline there is a fall in the overall perceived need for further palliative care education in the nine areas nominated. There are significant differences in the mean of aged care providers perceived educational needs for the following topics: pain assessment and management; end-of-life communication skill, giving bad news, talking with family, discussing prognosis and various treatment options, spirituality and cultural aspects of end-of-life care; dealing with terminal delirium; dealing with terminal dyspnoea; and use of intravenous hydration and/or non-oral feeding in end-of-life care.
Table 7-6: Aged care personnel’s future palliative care educational needs Time 1 and 2

<table>
<thead>
<tr>
<th>Palliative care educational needs</th>
<th>Time 1 (n=222)</th>
<th>Time 2 (n=183)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>m ± SD</td>
<td>m ± SD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Pain assessment and management</td>
<td>1.24 ± 0.43</td>
<td>1.54 ± 0.50</td>
<td>-6.31</td>
<td>0.00</td>
</tr>
<tr>
<td>2. Dealing with nausea and vomiting</td>
<td>1.58 ± 0.50</td>
<td>1.64 ± 0.48</td>
<td>-1.23</td>
<td>0.22</td>
</tr>
<tr>
<td>3. Dealing with constipation</td>
<td>1.65 ± 0.48</td>
<td>1.72 ± 0.45</td>
<td>-1.60</td>
<td>0.11</td>
</tr>
<tr>
<td>4. End-of-life communication skills, giving bad news, talking with family, discussing prognosis and various treatment options</td>
<td>1.24 ± 0.42</td>
<td>1.44 ± 0.50</td>
<td>-4.33</td>
<td>0.00</td>
</tr>
<tr>
<td>5. Spirituality and cultural aspects of end-of-life care</td>
<td>1.44 ± 0.50</td>
<td>1.62 ± 0.49</td>
<td>-3.63</td>
<td>0.00</td>
</tr>
<tr>
<td>6. Dealing with terminal delirium</td>
<td>1.30 ± 0.46</td>
<td>1.48 ± 0.50</td>
<td>-3.57</td>
<td>0.00</td>
</tr>
<tr>
<td>7. Dealing with terminal dyspnoea</td>
<td>1.37 ± 0.48</td>
<td>1.54 ± 0.50</td>
<td>-3.43</td>
<td>0.00</td>
</tr>
<tr>
<td>8. Use of IV hydration and/or non-oral feeding in end of life care</td>
<td>1.44 ± 0.50</td>
<td>1.61 ± 0.49</td>
<td>-3.31</td>
<td>0.00</td>
</tr>
<tr>
<td>9. End of life ethics; DNR orders, advance care directives, decision making capacity</td>
<td>1.37 ± 0.50</td>
<td>1.46 ± 0.50</td>
<td>-1.81</td>
<td>0.71</td>
</tr>
</tbody>
</table>
Survey participants at both Time 1 and 2, were predominantly middle aged women, who were employed as care assistants. This sample is representative of the skill mix in the residential aged care sector, where the majority of the workforce is composed of care assistants who are supervised by a small number of registered nurses. The only difference between this sample and the current Australian aged care workforce is the small number of nurses and care assistants who completed the survey from non-English speaking backgrounds and who identified as being Aboriginal or Torres Strait Islander peoples. This finding is not surprising given the Mid North Coast demographics and the small number of Aboriginal and Torres Straight Islander peoples employed as health care providers.

This survey was undertaken as part of an action research project. As discussed in Chapter Three the opportunity to collect data at two points in time, only emerged as the action research process unfolded. A deliberate decision at the outset of the project not to collect any identifying data from aged care providers prevented the samples from being matched. This decision was driven by a need to ensure that participants felt free to engage with the action research process without fear of identification and subsequent retribution. Despite this...
limitation, the survey was repeated at Time 2 in order to appraise the effect of the multifaceted intervention on aged care providers’ palliative care confidence and to identify areas for future practice change.

Although the samples are not matched, the increase in the mean age of participants from Time 1 to Time 2 corresponds to the length of time between the pre-test and post-test survey administration, suggesting a degree of employment stability within this rural aged care workforce. More limited employment opportunities in regional communities’ often means that aged care providers may resign from one aged care facility only to gain employment in a nearby facility. This workforce stability was evident in Coffs Harbour, with only a small number of aged care providers actually moving out of the area or ceasing to work in the local aged care sector. Consequently, aged care providers’ who acquired palliative care competencies during the R-PAC Project were largely retained within the local community. This degree of workforce stability is unlikely to occur in larger communities with greater employment choices and opportunities. This reality has implications for the development of other collaborative approaches to learning and development were the costs and benefits are more likely to be shared by all.

A larger percentage of aged care personnel at Time 2 had completed a short palliative care course, which reflects the provision of local palliative care learning and development strategies implemented for nurses and care assistants as part of the R-PAC Project. There is evidence that the multifaceted intervention has played a role in enhancing aged care personnel’s levels of independence to undertake a range of palliative care discussions with residents and their families, related to answering questions about the effects of medications, end-of-life care, preferred care environments, care wishes after death, discussing and managing frequently occurring palliative care symptoms, such as dyspnoea, delirium, and pain. This an important finding as enhanced care delivery is dependent upon the aged care workforce having better palliative care competencies in all of these areas\(^\text{12-16}\).

It is of interest that registered nurses reported less independence to provide information about local palliative care services at Time 2. Further exploration of this result is required as it is difficult to interpret, especially as similar ratios of nurses participated in the multifaceted intervention and were exposed to networking opportunities and information about local services.
Following the multifaceted intervention there was a positive difference in aged care providers’ ability to independently react to reports of resident’s pain. These providers also now had a more realistic understanding of the likelihood of older people developing respiratory depression and addiction secondary to their use of strong analgesics (opiates). Positive changes in aged care providers’ perceptions about who is the best judge of a person’s pain were also noted. As pain management is a key element of all good palliative care and previous research has identified that older peoples’ pain is generally poorly managed makes these important findings. Changing health care provider behaviour is a complex process, yet these findings confer some confidence that positive inroads have been made into providing local aged care personnel with the prerequisite knowledge, skills and attitudes to more effectively managed residents’ pain and other symptoms.

Overall these findings suggest that the multifaceted intervention played a role in addressing aged care nurses’ and care assistants’ expressed palliative care learning needs

7.3 Study H: A chart audit of end-of-life care

7.3.1 Aims

This chart audit sought to assess the impact of a multifaceted intervention developed using action research principles on the delivery of end-of-life care in nine residential aged care facilities in Coffs Harbour.

7.3.2 Methods

As described in Chapter Three, a prospectively modified ‘Liverpool End-of-Life Base Review’ (Appendix 5) was used to examine the level and type of palliative care provided to residents during the last 72 hours of life prior to the commencement of the R-PAC Project (Time 1). The chart audit was repeated twelve months into the implementation of the multifaceted intervention (Time 2). The audit tool facilitated standardised data collection. It is important to note that this chart audit was not intended to ascribe causality but to identify trends and identify areas for further practice development.
7.3.3 Sample

All residents who died in the nine aged care facilities during the last quarter of 2003 (Time 1) and 2005 (Time 2) were eligible for inclusion in the chart audit\(^{(17)}\). Residents who died in hospital were excluded from the study.

7.3.4 Data analysis

Data were entered into the Statistical Package for Social Science (SPSS) Version 14.0 to derive frequency estimates. Chi-square tests were used to compare percentages from Time 1 and the Time 2 data sets, with \( p < 0.05 \) being taken to indicate statistical significance. All data has been reviewed and confirmed by a statistician.

7.3.5 Results

Eighty one deceased residents’ medical records met the inclusion criteria, with 38 consecutive medical records being audited in the Time 1 period and 43 medical records at Time 2 (Table 7-7\(^{(17)}\)). The majority of deceased residents who died were females with the proportion increasing from Time 1, 61% \((n=23)\) to Time 2, 77% \((n=33)\). There was a trend towards residents dying at an older age, with the mean (SD) age in years at Time 1, 84 \([SD \pm 9.5]\) years increasing at to Time 2, 87 \([SD \pm 6.9]\). The major causes of a resident’s death were related to complications from cardiovascular disease (Time 1, 31% versus Time 2, 23%) and frailty (Time 1, 29% versus 26%)\(^{(17)}\). A smaller proportion of resident’s deaths were directly attributed to malignancy (Time 1, 16% versus Time 2, 21%) and complications from advanced dementia (Time 1, 16% versus Time 2, 14%)\(^{(17)}\).

Frailty was a common syndrome experienced by the majority of deceased residents (Time 1, 66% versus Time 2, 79%). There were high levels of co-morbidity amongst these older people, with two thirds of residents known to have cardiovascular disease (Time 1, 58% versus Time 2, 61%), while almost half (47%) at both points in time having a neurological condition and some degree of cognitive impairment (Time 1, 53% versus Time 2, 51%). There were no statistical differences in terms of age, gender, primary and secondary diagnoses between the Time 1 and Time 2 groups (Table 7-7\(^{(17)}\)).
Table 7-7: Demographic data, primary and secondary diagnoses at time of death Time 1 and 2

<table>
<thead>
<tr>
<th>Sample</th>
<th>Time 1</th>
<th>Time 2</th>
<th>p values</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n =38</td>
<td>% (100)</td>
<td>n =43</td>
</tr>
<tr>
<td>Age (years) mean [SD]</td>
<td>84 [± 9.5] years</td>
<td>87 [± 6.9] years</td>
<td>0.23</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15 (39)</td>
<td>10 (23)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>23 (61)</td>
<td>33 (77)</td>
<td></td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td></td>
<td></td>
<td>0.81</td>
</tr>
<tr>
<td>Malignancy</td>
<td>6 (16)</td>
<td>9 (21)</td>
<td></td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>6 (16)</td>
<td>6 (14)</td>
<td></td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>12 (31)</td>
<td>10 (23)</td>
<td></td>
</tr>
<tr>
<td>Respiratory disease</td>
<td>2 (5)</td>
<td>5 (12)</td>
<td></td>
</tr>
<tr>
<td>Neurological condition</td>
<td>1 (3)</td>
<td>2 (5)</td>
<td></td>
</tr>
<tr>
<td>Other/fragility</td>
<td>11 (29)</td>
<td>11 (25)</td>
<td></td>
</tr>
<tr>
<td>Secondary diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malignancy</td>
<td>3 (8)</td>
<td>9 (21)</td>
<td>0.90</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>20 (53)</td>
<td>22 (51)</td>
<td>0.81</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>22 (58)</td>
<td>26 (61)</td>
<td>0.89</td>
</tr>
<tr>
<td>Respiratory disease</td>
<td>8 (21)</td>
<td>7 (16)</td>
<td>0.62</td>
</tr>
<tr>
<td>Neurological condition</td>
<td>18 (47)</td>
<td>20 (47)</td>
<td>0.97</td>
</tr>
<tr>
<td>Fragility</td>
<td>25 (66)</td>
<td>34 (79)</td>
<td>0.96</td>
</tr>
<tr>
<td>Musculoskeletal conditions</td>
<td>12 (32)</td>
<td>13 (30)</td>
<td>0.21</td>
</tr>
<tr>
<td>Other</td>
<td>22 (58)</td>
<td>28 (65)</td>
<td>0.42</td>
</tr>
</tbody>
</table>

* Total responses > 100% indicate more than one secondary diagnosis

Medication management

The majority of residents were able to swallow at both 72 (74% at Time 1 and 2) and 24 hours prior to death (Time 1, 55% versus Time 2, 65%) (Table 7-8). At 72 hours at Time 2 residents were using 5.19 medications [SD ±3.1] compared to Time 1, 4.57 medications [SD ±2.6]. This trend persists at 24 hours when 4.2 [SD ± 3.3] medications were in use at Time 2, versus 3.9 [SD ± 2.7] medications at Time 1. Although at Time 2 more residents had their
non-essential medications ceased (51% versus Time 1, 32%), this group were more likely to continue to receive their analgesics (93% versus Time 1, 84%), cardiovascular medications (49% versus Time 1, 42%), laxatives (44% versus Time 1, 21%) and antipsychotic medications (26% versus Time 1, 5%) (Figure 7-6).

Table 7-8: Medication management in last 72 and 24 hours Time 1 and 2

<table>
<thead>
<tr>
<th>Sample</th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n= 38 % (100)</td>
<td>n=43 % (100)</td>
</tr>
<tr>
<td>Resident able to swallow at 72 hours</td>
<td>28 (74)</td>
<td>32 (74)</td>
</tr>
<tr>
<td>Non essential medications ceased 72 hour</td>
<td>12 (32)</td>
<td>22 (51)</td>
</tr>
<tr>
<td>Medications in use at 72 hours</td>
<td>4.57 (SD ±2.6)</td>
<td>5.19 (SD ±3.1)</td>
</tr>
<tr>
<td>Resident able to swallow at 24 hours</td>
<td>21 (55)</td>
<td>28 (65)</td>
</tr>
<tr>
<td>Medications in use at 24 hours</td>
<td>3.9 (SD ± 2.7)</td>
<td>4.2 (SD ± 3.3)</td>
</tr>
</tbody>
</table>

Figure 7-6: Summary of medications ordered at 72 hours at Time 1 and 2

Symptom assessment and management

Similar level of symptom burden was observed in each group (Time 1, 1.38 symptoms [SD ± 0.96] versus 1.6 [SD ± 1.05] symptoms at Time 2) (Figure 7-7).
Pain was the most common symptom experienced by residents in the last 72 hours of life (Time 1, 63% versus Time 2, 61%). However, at Time 2 there were a greater number of regular opiate orders (72% versus Time 1, 53%) and fewer regular simple analgesic orders (44% versus Time 1, 58) (Figure 7-8). At Time 2, there were also more regular subcutaneous opiate orders (41% versus Time 1, 34%) and PRN subcutaneous opiate order (35% versus Time 1, 26%). Residents who experienced pain were more likely to have their pain regularly assessed at Time 2 (46% versus Time 1, 16%) with an appropriate pain assessment tool being used (42% versus Time 1, 0%). Residents at Time 2 were also more likely to be given analgesia for their break through pain (73% versus Time 1, 25%).
Restlessness and agitation was experienced by more residents at Time 2 (37% versus Time 1, 18%) making it the second most common symptom (Figure 7-7). Residents were more likely to have their restlessness assessed at Time 2 (56%, versus Time 1, 29%), with other causes of restlessness and agitation also being considered more frequently at Time 2 (56% versus Time 1, 0%). Sedation on a PRN basis was given more frequently to manage restlessness and agitation in the last 72 hours at Time 2 (63% versus Time 1, 14%) (Figure 7-9). Although low levels of confusion and delirium are reported at both points in time (Time 1, 16% versus Time 2, 7%), there are differences in the prescribing of regular antipsychotics (Time 1, 8% versus Time 2, 26%) as well as PRN subcutaneous antipsychotic orders (Time 2, 9% versus Time 1, 0%) at 72 hours (Figure 7-6). More antipsychotics are given to manage residents’ episodes of confusion and delirium at Time 2 (33% versus Time 1, 17%).
Dyspnoea was experienced by almost a fifth of all residents (Time 1, 24% versus Time 2, 21%) (Figure 7-7). Residents at Time 2 who experienced episodes of dyspnoea in the last 72 hours of life were more likely to be given a PRN opiate (56% versus Time 1, 0%), a PRN anti-anxiety agent (22% versus Time 1, 0%) and/or PRN oxygen (67% versus Time 1, 33%) (Figure 7-10). More residents at Time 2 (19% versus Time 1, 10%) also experienced excessive respiratory tract secretions. A PRN subcutaneous anticholinergic was more likely to be prescribed to manage this symptom at 72 hours at Time 2 (14% versus Time 1, 0%), while a smaller number of residents had a regular subcutaneous anticholinergic order at 24 hours (9% versus Time 1, 3%) (Figure 7-10). During the last 24 hours of life there was an increase in the number of residents with an anticholinergic order at Time 2 (16%, versus Time 1, 3%).

**Figure 7-9**: Management of restlessness/agitation and confusion/delirium at Time 1 and 2
Few residents experienced nausea and vomiting (Time 1, 11% versus Time 2, 14%) (Figure 7-6) and this is reflected in the low levels of anti-emetics prescribed (Time 1, 8% versus Time 2, 12%) (Figure 7-6).

**Documented level of palliative care provided**

There was no evidence of residents receiving any form of artificial hydration at either point in time. Reassuringly the majority of residents at both Time 1 (97%) and Time 2 (95%) were provided with what was classified as ‘comfort care’\(^{(18)}\). Comfort care occurs when the natural process of dying is permitted to occur and the care that is provided is focused on maximising comfort and dignity and minimising distress\(^{(19)}\).

Although just over half of the residents in both groups were aware of their diagnosis (Time 1, 53% versus Time 2, 58%) and documentation revealed more residents at Time 2 were aware they were dying (35% versus Time 1, 16%) (Figure 7-11). Increased communication with families was evident at Time 2, which is illustrated by them being more likely to be informed of the resident’s impending death (86% versus Time 1, 66%). General practitioners were also more likely to be informed of the deterioration in the resident’s status at Time 2 (88% versus Time 1, 68%) (Figure 7-11).

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**Figure 7-10**: Management dyspnoea and excessive respiratory secretions at Time 1 and 2
There was a larger percentage of DNR orders at Time 2 (40% versus Time 1, 24%), do not transfer to hospital orders (40% versus, Time 1, 34%) and a documented advance care plan (51% versus Time 1, 34%). While residents at Time 2 were more likely to receive specialist palliative care input (26% versus Time 1, 5%) and to have their end-of-life care planned by a multidisciplinary team (30% versus Time 1, 8%) (Figure 7-11).

![Figure 7-11: Level of palliative care provided at Time 1 and 2](image)

At both Time 1 and 2 there was evidence of high quality nursing care being provided to residents at the end-of-life with attention being paid to their personal care needs (Figure 7-12). Very few residents required wound care (10%, Time 1 versus 14%, Time 2). In addition, indwelling catheters (IDC) were rarely used to manage urinary incontinence (3%, Time 1 versus 7%, Time 2) with incontinence pads more likely to be used (79%, Time 1 versus 84%, Time2).
Figure 7-12: Level of nursing care provided at Time 1 and 2

7.3.6 Reflections on the findings

The profile of the residents included in this audit mirrors the current Australian residential aged care population where the majority of residents are over 85 years of age, female, with some degree of cognitive impairment and are likely to die from complications of a progressive life limiting illnesses (3, 20-23). Similar to other studies the majority of residents died from complications associated with non-malignant diseases, primarily advanced dementia and cardiovascular disease (24, 25). However, as the population continues to age the incidence of older people with cancer may increase and this has implications for care giving, particularly in the aged care setting (26).

The incidence of frailty reflects the high levels of chronic disease states experienced by residents (27). The presence of frailty in older adults is suggestive of a ‘…clinical state of vulnerability with inherent increased risks of poor outcomes…’ (27)(p.106). Although all potentially treatable cause of frailty ought to be identified and treated, very often the underlying cause(s) cannot be identified and if identified, many of the causes are not reversible (28), which makes frailty is an important predictor of decline in older people.

The level of symptom burden reported in this study is similar to that reported by Brandt et al. using proxy ratings (25) in dying residents but less than the three or more symptoms reported by...
Hall and colleagues (24) As previously discussed in Chapter Four, this variation in symptom burden may reflect the different audit tools that were used as the modified ‘Liverpool End-of-Life Base Review’ audit tool was developed from a malignant perspective and focuses on six main symptom clusters common at 72 hours: pain, nausea and vomiting, excessive respiratory secretions, dyspnoea, restlessness and agitation, and confusion and delirium (2). The tool used by Hall and colleagues (24) notes the presence of dysphagia, fever and myoclonus or other symptoms in the last 48 hours. Alternatively, as underlying disease may determine the patterns of symptoms (25) the findings reported may reflect less symptom burden in this elderly cohort who largely died of non-malignant disease and whose care could be effectively managed within the aged care facility. Further, it may also be indicative of the overall high quality of care provided in these facilities (25). As expected there were low levels of medical intervention amongst this sample of residents, which is markedly different to the medical intervention that older people with dementia dying in the acute care sector experience (29).

The number of residents who experienced pain in this study at Time 1 and 2 is similar to that reported for older people dying in the acute care (24) and aged care settings (26). Reassuringly the majority of residents were ordered regular analgesics with a trend towards improved pain management at Time 2 with residents’ pain being more systematically assessed, with more appropriate prescribing of analgesics, including greater use of opiates and PRN opiate orders for break through pain. Despite this positive trend, there is still considerable scope to embed the routine use of pain assessment tools as a foundation for sound clinical practice (17, 30).

Although previous studies have found that the input of specialist palliative care teams improved resident’s pain management (31), the degree to which this impacted on these findings cannot be determined. There is evidence that there was greater specialist palliative care input at Time 2 and more multidisciplinary care planning, but sampling considerations preclude us from making any definitive conclusions. The trends noted in this study are encouraging particularly as effective pain management is an essential component of end-of-life care (32-34).

Similar levels of dyspnoea were experienced by residents in this study to those reported by Brandt and colleagues (25). Minimising the distress caused by dyspnoea requires effective management that is dependent upon assessment and planning (3, 24). The higher use of opiates and anti-anxiety agents to manage residents’ dyspnoea at Time 2 suggests a greater appreciation amongst the care team of the importance of implementing appropriate symptom management strategies for dyspnoea (3, 35). Excessive respiratory secretions are frequently experienced by dying people (2) and within specialist palliative care, PRN anticholinergic
agents are often used to manage this symptom. Although a small number of residents experienced excessive respiratory secretions, PRN anticholinergics were only prescribed and used for residents at Time 2. This finding infers greater awareness amongst aged care providers of current evidence based therapies to manage this symptom. Restlessness and agitation is another common end-of-life symptom. At Time 2 there was a tendency for aged care personnel to consider alternative causes for a resident’s restlessness, which suggests an appreciation of the role of thorough and informed assessment and the importance of exploring non-pharmaceutical interventions before resorting to sedation\(^{3}\). The trend towards increased assessment of symptoms and more appropriate prescribing and administration of a range of medications to manage common end-of-life symptoms is a positive finding. Unfortunately, this action research study was unable to control for confounders, such as new medication listings and pharmaceutical education that may also have occurred during the study period and which could also have influenced these findings.

The reduction in medications in use at 24 hour reflects the resident’s deteriorating status and the cessation of non-essential medications. At both times, over half of the residents in this study were still able to swallow during the last 24 hours of life, suggesting that they were still conscious. This finding is in line with another study that found that less than half (44%) of residents were unconscious 24 hours before death\(^{25}\). The consciousness state of residents may have delayed the ceasing of their non-essential medications and limited identifying imminent death, which was only evident for half of the residents. This observation suggests that some of the traditional clinical markers used to help identifying dying, based on a malignancy paradigm may not be entirely applicable to this largely frail, elderly cohort with chronic co-morbid conditions\(^{13}\). It also reinforces the importance of adopting a palliative approach and establishing a multidisciplinary team to plan the residents’ care well in advance to the terminal phase of their illness\(^{36, 37}\).

For the other half of the residents, their deterioration was more subtle and occurred over an extended period of time. For these residents, deterioration appears to be more akin to ‘fading away’ with the slow gradual illness trajectory being punctuated by sudden acute and reversible illnesses as described by Lynn et al\(^{38}\). This suggests that incremental events, such as persistent or recurrent infections, repeated falls, weight loss, cognitive decline, progressive disengagement in normal activities and other affective changes may have more relevance as predictors of decline in the frail aged\(^{37}\).
Challenges implementing palliative care in these slow, progressive illnesses is well documented\(^{(14, 23, 38)}\). Although the use of an end-of-life integrated clinical pathway may promote better evidence based care for dying residents\(^{(2, 39)}\) these pathways are based on linear temporal models and have been largely configured to address procedural issues in acute care\(^{(40)}\). In contrast this study’s findings identifies a model of fragility and slow deterioration from which it is inferred that a modified end-of-life care pathway approach is required\(^{(2, 41, 42)}\). This study’s data suggest that symptom based pathways that are implemented well before the last days of life may have greater utility in the aged care setting.

This audit found greater evidence of discussions with families about the resident’s impending death at Time 2. It is also inferred from these findings that aged care personnel have more confidence to initiate these end-of-life discussions, suggesting a greater level of comfort around death and dying issues\(^{(3, 43, 44)}\). Despite this positive trend, this study found sub-optimal documentation of resident’s end-of-life care preferences with little evidence of a systematic approach being employed, which is similar to that reported elsewhere\(^{(36)}\), except that this study does reports higher levels of ‘do not transfer to hospital orders’. The advanced age of residents combined with their level of disability and cognitive impairment makes advance care planning a priority that warrants greater attention.

7.3.7  **Study strengths and limitations of Study H**

Study H has several limitations. Firstly, using chart audits as the methodology for this study may have lead to some bias as the method depends on the quality of documentation in the resident’s notes and the completeness of the records. It is also possible that the care provided to residents may not have been fully documented. Much of the documentation in resident’s notes appeared to have been shaped by the information and language required to meet the current aged care funding formula criteria\(^{(45)}\). In addition, many of the notes were written by care assistants, who provide the bulk of the direct personal care with minimal formal education and training\(^{(10)}\). Further, the action research approach may have induced a Hawthorne effect and deaths occurring following the intervention were not blinded to assessors\(^{(46)}\). The need to assess data entries in chart audit made the blinding of assessors prohibitive. The absence of a control group, the heterogeneity of the intervention and a large number of extraneous variables limit extrapolation to other settings and impede the ability to confirm that the improvements observed were directly attributable to the multifaceted intervention\(^{(46)}\). Nevertheless, the trends reflected in these data are encouraging particularly as the aged care providers including medical, nursing and care assistants remained consistent.
over the intervention period and the similarity in baseline clinical characteristics across the two measurement points.

Despite these limitations, this study has several strengths. Firstly, within the context of an action research project these data have provided insight to fuel project development. Secondly, the study has systematically described the clinical and demographic characteristics of people dying in an Australian residential aged care. To date this population is poorly characterised\(^{(47)}\). Overall this audit confers some confidence in the efficacy of the action research process to enhance knowledge and drive clinical improvements. Importantly, these data will be useful to power further intervention studies and have generated hypotheses, particularly in relation to the observed reluctance to document end-of-life preferences and resistance to systematic assess resident’s pain. The findings of Study H underscore the importance of increasing the evidence base for palliative care in non-malignant conditions, such as advanced cardiovascular disease, dementia and frailty\(^{(14, 21, 44)}\). They also highlight the complexity of palliative care strategies for those with cognitive impairment\(^{(29, 48-57)}\), particularly related to assessment, effective symptom management and developing appropriate clinical markers.

7.4 Conclusion

The caveats of the study design are well acknowledged in terms of assigning attribution of causality. In spite of the inherent biases inferred by the study methodology, as discussed above; Study G and Study H have demonstrated a trend towards enhanced symptom management, increased levels of confidence and more appropriate levels of palliative care for people dying in residential aged care following implementation of the R-PAC Project. The following chapter seeks to draw all of the elements of the R-PAC Projects together, addressing the impact of the action research process and summarising the implications of this project for clinical practice, policy and research.
7.5 **Reference list**


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Chapter 8.

Conclusion: Implications of the R-PAC Project and Navigating a Course for Future Action
‘Coming together is a beginning. Keeping together is progress. Working together is success’

Henry Ford

8.1 Introduction

This research has demonstrated the value of action research in collaboratively driving change within the residential aged care setting in a regional community. At the outset, the ‘Residential Palliative Approach Competency’ Project’s’ overarching aim was to address the unmet palliative care needs of older people in nine aged care facilities in regional Australia using a population based focus. Following an appraisal of the social, political and economic context of local residential aged care, an action research process was considered to be the methodology most likely to achieve the R-PAC Project’s aim. It was also considered that this approach would fuel a change process that was educational, empowering and emancipating and help pave the way for other clinical practice improvement initiatives in this setting.

This final chapter of this thesis draws together the findings of the R-PAC Project’s eight sub-studies which can be divided into three main themes: i) the positive changes achieved in the course of the project; ii) challenges encountered in changing health care practice; and iii) focus for ongoing action. This chapter seeks to summarise answers to the research questions posed in Chapter One. It also reflects on the action research process; addresses the strengths and weaknesses of the study design as well as detailing the implications of the R-PAC Project’s findings for clinical practice, research and policy.

8.2 Key findings

The answers to the research questions posed by this thesis are summarised below.

(a) What are the population based palliative care needs of older people living in residential aged care in Coffs Harbour, New South Wales?

The focused needs assessment documented a rapidly growing and ageing population on the NSW, Mid North Coast. Despite the increased emphasis on community based care, it was identified that many older people with care needs greater than community resources inevitably required admission to an aged care facility. The PRECEDE framework\(^1\) assisted with defining the current scope and depth of the palliative care needs of older people in Coffs Harbours nine aged care facilities\(^2, 3\). Legislative, demographic and societal changes have forced the aged care sector to continually evolve so they are now required to play a more
significant role in the care of older people who are dying\cite{4-6}. The popularity of the Mid North Coast as a preferred retirement destination\cite{7} combined with an increased incidence of age related progressive life limiting illnesses suggested that local aged care facilities would increasingly be required to deliver palliative care and end-of-life care. Admission to aged care is frequently required because many older people have complex care needs that exceed community based resources and often lack the support of a full time primary care giver\cite{8}. Consequently, local aged care facilities are increasingly functioning as slow stream hospices\cite{9-11} and this demand is expected to continue. The majority of older people admitted to this care setting have specific high care needs and are likely to die within 24 months of admission, suggesting that they will have limited time to adjust to their new setting\cite{12, 13}. These demographic and epidemiological changes made promoting the delivery of a palliative approach in local aged care facilities a priority for this regional Australian community.

\textit{(b) What are the key factors in facilitating palliative care delivery in residential aged care within this regional community?}

Applying the lessons from the PRECEDE health promotion model allowed for a more expansive exploration of the facilitators and barriers to effective and efficient palliative care delivery to older people in aged care facilities in Coffs Harbour\cite{1}. Several critical enabling factors were identified in the course of the R-PAC Project. Firstly, at a National level there was a recognition that evidence based palliative care ought to be made available for all Australians with a progressive life limiting illness in accordance with need, regardless of their age, diagnosis, geography and care setting\cite{14-17}. As a consequence a range of national program initiatives have been developed to address these care deficits, including a specific focus on the needs of older people in aged care facilities, rural Australians and people with non-malignant conditions\cite{15, 18, 19}.

The selection of Coffs Harbour as one of the eight demonstration sites for the National Rural Palliative Care Program in late 2003\cite{18} was a major facilitator for this research. This initiative afforded a unique opportunity to this rapidly growing and ageing regional community to extend palliative care out to hard to reach populations by strengthening local partnerships. Having ready access to a range of resources helped address some of the barriers that have previously been noted to hamper health service reform\cite{20} and enabled the nine aged care facilities to actively engage in the R-PAC Project’s multifaceted intervention.

Another critical facilitator was the release of evidence based palliative approach guidelines in early 2004\cite{21}. These national guidelines fuelled further interest and momentum for the R-
PAC Project. They also provided a contextual framework for determining the level of palliative care required in accordance with each resident’s individual need and assisted in mapping out a pathway for aged care personnel to determine when a palliative approach, specialist palliative care input or end-of-life care was indicated. A combination of clear national guidance about the standards and criteria to be implemented, along with the allocation of significant resources provided the leverage required to prime the local aged care environment for change\(^{(20)}\).

Importantly, at the outset of the R-PAC Project there was a commitment by aged care personnel to work collaboratively to implement a palliative approach. This commitment was reflected in the manner in which personal and nursing care was provided to residents dying in local aged care facilities\(^{(22)}\), local aged care personnel’s desire to have greater palliative care competencies\(^{(11)}\) and the confidence to deliver best evidence based palliative care to residents and their families\(^{(23)}\). Finally, but of equal importance, was local aged care personnel’s preparedness to collaboratively explore new models of care that would integrate the delivery of a palliative approach across the nine local residential aged care facilities using a population focus.

(c) What are the major barriers to palliative care delivery in residential aged care within this regional community?

The needs assessment data set\(^{(11, 22-26)}\) enabled the identifying of barriers that could be broadly categorised into, consumer (residents and their families), provider (aged care nurses, care assistants and general practitioners) and system issues that needed to be addressed at a local, State and National level.

The consumer issues to emerge from these data at the outset of the R-PAC Project revealed sub-optimal symptom management, particularly pain management, inadequate advance care planning, limited formal engagement of families in care planning, limited discussions around death and dying and end-of-life care preferences, and unclear lines of responsibility between health care providers\(^{(11, 23, 26)}\). Despite death being a consistent presence in local aged care facilities this topic was not routinely raised or discussed in an open and honest manner with residents and their families\(^{(11, 27)}\). A lack of confidence in initiating end-of-life discussions combined with a focus on healthy ageing and rehabilitation\(^{(6)}\) have all contributed to aged care personnel’s discomfort in broaching this subject. This was identified as a major barrier to the delivery of a palliative approach\(^{(11)}\).
The participatory processes of action research allowed aged care nurses, care assistants and general practitioners to be supported in defining and addressing the barriers limiting the delivery of evidence based palliative care to residents\(^{(22, 25)}\). Adopting this collaborative approach enabled the researcher to gain a deeper and richer understanding of the phenomena under investigation\(^{(28)}\). This exploration revealed that many of the barriers to effective palliative care delivery within local aged care facilities have their roots in the disparity of power, education and status of aged care personnel. Collectively these inequalities were effectively limiting aged care personnel ability to assert their concerns both within and outside of the organisation in a manner that would be understood, respected and acted upon\(^{(11, 23)}\). At the outset of the R-PAC Project few local aged care providers had undertaken any palliative care education with most only having ‘on the job training’\(^{(23)}\). In addition, they were also quite isolated from other health care providers and had limited knowledge of existing local palliative care resources\(^{(11, 23)}\). As a consequence, the specialist palliative care team had little input into the management of resident’s care\(^{(11, 23)}\).

Another significant barrier was accessing timely medical input for residents\(^{(11)}\). Despite the general practitioner being the key provider of medical care to older people in aged care facilities several system barriers were identified that limited their availability, including: a local shortage of general practitioners; the burden of regulatory processes; discordant communication with other health care providers; time issues; and poor remuneration\(^{(22)}\). These systems issues have prompted some doctors to cease visiting aged care facilities, further exacerbating the challenges of securing timely medical assessment and intervention for residents\(^{(11, 25, 29)}\). In addition, few general practitioners have undertaken any formal palliative care training and their lack of awareness of the emerging paradigm of a palliative approach indicated for older people further limits residents’ access to best evidence based palliative care\(^{(11, 25, 29)}\).

While clinical and practice guidelines exist for residential aged care, these are not always nationally consistent or linked to the standards under the current legislation\(^{(30, 31)}\). This anomaly has been identified as leading to inconsistencies in applying best practice in aged care homes\(^{(32)}\). At this stage the palliative approach guidelines have not been fully reflected in the Australian aged care standards, which is of concern, because these standards currently emphasise that palliative care is indicated for terminally ill residents\(^{(31)}\). Unfortunately, this focus acts to reinforce the inappropriate notion that palliative care is only indicated for people who are dying. This is compounded by the absence of robust clinical indicators which makes
it difficult to accurately pinpoint the resident’s transition to the terminal phase\(^{26}\). These factors have previously limited resident’s access to timely palliative care to manage symptoms associated with prolonged deterioration. Not initiating palliative care until the person is actually dying is of limited value for the majority of residents because they tend to experience a slow and gradual decline, as described by Lynn and colleagues\(^{33}\) and demonstrated in Studies B and H\(^{26}\). The ambiguity created by this discord impacts on aged care personnel’s confidence to accurately determine when palliative care is indicated\(^{26}\). In an environment of increasing technological complexity, where older people with higher acuity are increasingly being managed within residential aged care for shorter periods of time before dying, suggests that these factors need to be addressed in order to enhance palliative care delivery\(^{11, 23, 26}\).

\(d\) What are the palliative care knowledge, skills, attitudes and beliefs for clinicians working in residential aged care within this regional community?

The R-PAC Project’s needs assessment data identified that nurses and care assistants were enthusiastic about enhancing their palliative care competencies but had limited opportunities for acquiring this new knowledge and skills locally\(^ {11}\). The needs assessment data also revealed that aged care personnel held ambivalent views towards pain management, particularly at the end-of-life and had some misconceptions about opiate usage and when it should be introduced\(^{23}\). Care assistants, who tend to have less educational preparation, indicated greater uncertainty about a range of ethical care issues. They were uncertain about whether or not artificial hydration was appropriate, whether families had a right to refuse treatment, and whether the residents’ general practitioner was the most appropriate person to make end-of-life decisions. These care assistants were also uncertainty about what exactly denoted best care\(^{23}\). These are complex care issues that raise various moral, ethical and legal questions\(^{23}\). Addressing these uncertainties required a multifaceted intervention with the scope to focus on the knowledge, skills, attitudes and behaviours of all aged care personnel.

The data collected after the intervention showed that for care assistants, the learning and development strategy had been an empowering experience, validating the importance of their role in the care team\(^ {22}\). Being introduced to a range of clinical tools had helped them to verify their observational skills and aided in the reporting of clinical observations in a meaningful format\(^{34, 35}\). This is turn, promoted greater teamwork and helped improve nurses’ and care assistants’ relationships. Acquiring the vocabulary required to effectively report their clinical observations ensured that these personnel were now more confident to use
the specialist language\textsuperscript{(22)}. The intervention provided aged care nurses and care assistants with an understanding of the knowledge, rules and norms, accepted terms and codes, which make up the specialist language of palliative care\textsuperscript{(36)}, and this effectively put them on a par with other health care providers\textsuperscript{(22)}. Having these competencies enabled the nurses to join conversations and play a key role in determining the care the residents received. In effect, the multifaceted intervention has given these nurses and care assistants ‘a voice at the table’ and helped to increase their personal confidence and fostered a sense of worth and satisfaction\textsuperscript{(22)}.

At a professional level, the opportunities afforded by the multifaceted intervention were highly valued and there was a desire for these strategies to be ongoing. The intervention increased the palliative care knowledge, skills and confidence of nurses and care assistants, facilitating a palliative approach. Access to palliative care information and appropriate resources facilitated the provision of evidence-based palliative care\textsuperscript{(22)}. The intervention also increased aged care nurses’ and care assistants’ confidence and competencies to engage in discussions with families and, given the high incidence of cognitive impairment amongst residents, this is critical for facilitating greater care collaboration, enhanced decision making and assisting to define the goals of care\textsuperscript{(22, 37)}. The number of residents who received their end-of-life care within the aged care sector increased over the course of the R-PAC Project, suggesting that residents, their families and age care providers felt more confident about managing the resident’s end-of-life care within the facility.

The use of validated assessment tools removed some of the uncertainty for aged care personnel regarding what is clinically relevant and required to be communicated to others, and as a consequence, enhanced teamwork\textsuperscript{(37)}. Of interest and significance, the intervention allowed insight into the importance of a team approach and how each provider’s role makes a unique contribution to the resident’s care experience. Individual beliefs, previous education and training all shape perceptions regarding the care of residents, recognising the unique role each provider plays is an important step towards the creation of a collaborative approach to care delivery\textsuperscript{(38, 39)}.

The multifaceted intervention has also provided opportunities for interactions with the specialist palliative care team, cross-facility networking opportunities, thereby decreasing professional isolation and increased aged care nurses’ abilities to elicit timely assistance and support\textsuperscript{(22)}. Participation in the specialist palliative care multidisciplinary team meeting had also helped to validate and value aged care nurses’ unique role, gerontological competencies and to acknowledge the inherent challenging often associated with providing care in this
There was also a perception that the intervention was effective in increasing aged care personnel’s palliative care competencies and confidence, helping them acquire the specialist language of palliative care, and improving their palliative care networks. The R-PAC Project has demonstrated the power of the action research process in engaging clinicians as active partners in the developing of a tailored multifaceted intervention to increase the palliative care competencies and confidence of aged care nurses and care assistants.

(e) What are the information needs, resources and systems required for the successful delivery of a palliative approach to end-of-life care in residential aged care facilities in this regional community?

Over the three years of the R-PAC Project, a range of information needs, resources and systems have been identified as being required to augment a palliative approach within Australian residential aged care facilities. Enhancing the palliative care competencies of aged care nurses and care assistants is a key element required for adopting best evidence based practice. This has been achieved through the implementation of a multifaceted intervention, focussing on tailored learning and developing appropriate strategies. In developing the learning strategies consideration was given to the diversity in knowledge and skills in the aged care workforce. This diversity dictated that the R-PAC Project uphold and reinforce adult education principles. This meant that participation in the learning opportunities was voluntary and that the sessions matched and built on people’s life experiences and understandings, whilst ensuring that participants’ gained critical insights and new skills. These sessions also needed to encouraging critical reflection. Whilst acknowledging the importance and need for greater knowledge and skills this approach also allowed for exploration of highly personal and often contentious beliefs associated with ageing, opiate usage and death and dying issues. Adult education provided the greatest opportunity for behaviour change by using experiential learning strategies that were both empowering and focussed on knowledge, skills and attitudes. These strategies, along with networking and action learning opportunities, enhanced the capacity of aged care personnel to communicate more assertively and equally in formal decision making arenas.

The R-PAC Project reinforces the importance of the serendipitous presence of ‘early adopters’ to catalyse and organise enthusiasm for a new initiative to be tested in the workplace. In disempowered communities early adopters are often required to act against community norms in order to achieve change. In the R-PAC Project the early adopters, were initially the director of nursing and subsequently the link nurses, who all self-selected for this role. These nurses were critical change agents who promoted and endorsed the
delivery of a palliative approach within their individual residential aged care facility. They also supported and encouraged other aged care personnel, particularly care assistants to engage in the opportunities afforded by the R-PAC Project and promoted policy and practice change within their individual facilities to facilitate the delivery of a palliative approach.

The input of the directors of nursing was essential for ensuring that the high level organisational support and commitment for the delivery of a palliative approach within each aged care facility was provided, along with the systems and infrastructure changes required to support this new type of care delivery. In addition, each link nurse was responsible for conducting in-house palliative care education and implementing practice and policy changes as part of the quality improvement processes to enhance the delivery of a palliative approach.

The degree to which this role was undertaken is not known, and ought to be the focus of additional research. On reflection it would seem that in recruiting and training interested registered nurses to take on the link nurse role it may be more efficacious if they could gain the skills and confidence required to effectively motivate, lead and play a key role in driving organisational change role within their aged care facility.

Attrition is an issue in the Australia aged care workforce and this was experienced in the R-PAC Project link nurse strategy, with some of these change champions leaving the area while other sought employment within another local aged care facility. Arranging a replacement link nurse and providing them with access to relevant learning and development opportunities within a tightly choreographed program presented numerous challenges for the R-PAC Project. Establishing and support the link nurse initiative in the smaller low care facilities proved to be particularly challenging, especially given that these facilities often only employed no more than three registered nurses. This difficulty suggest that a critical mass of registered nurses may be required to enable the link nurse role to become established and fully functional within aged care facilities, although this requires further research.

In several aged care facilities it was challenging to engage participants in the R-PAC Project’s Palliative Care Workshop for registered nurses. The lower than anticipated participation rates may have been related to a diverse range of factors, such as: i) fewer registered nurse employed within the facility which limits their ability to be released; ii) an older cohort of older registered nurses who are closer to retirement and therefore potentially less interested in embarking on new educational experiences; iii) acquiring additional competencies may be a risk factor for increased responsibility and workload; iv) a higher proportion of part-time
workers; v) access to in-house palliative care education, and/or vi) a perception that they already had adequate palliative care competencies.

These are important area for further investigation, particularly given the focus on maintaining older workers in the workforce and the recruitment and retention challenges faced by the aged care sector\(^\text{46}\).

The findings of the mixed method approach were synthesised to identify factors impacting on a personal, professional and organisational level (Table 8-1). The overall assessment of the multifaceted intervention revealed that it has positively impacted on aged care nurses and care assistants at a personal, professional and organisation level. Importantly, increased competencies and confidence have impacted positively on the care provided to residents at the end of life\(^\text{26}\).

Care assistants and enrolled nurses embraced the learning and development opportunities afforded them with all of the all workshops being fully subscribed and the majority of participants completing the entire course. For these unregulated workers’ and enrolled nurses’ acquiring palliative care competencies was an empowering experience, helped validate the importance of their roles and enabled them to work more effectively as team members\(^\text{22}\). This research also supports the notion that empowerment is a labour intensive, long term process achieved through many actions\(^\text{49}\).

The importance of regular multidisciplinary review of all residents and families care needs was a key outcome of the R-PAC Project. A process to facilitate the multidisciplinary review of residents in accordance with their individual needs underpinned by a palliative approach has been detailed in Chapter Six. To further assist with this process, and informed by the R-PAC Project data, a checklist developed by Kessler and colleagues\(^\text{50}\) was modified by the Critical Reference Group and adopted for use\(^\text{50}\). The original checklist was developed to assist aged care personnel to identify imminent dying and to promote appropriate care planning\(^\text{50}\). The modifications undertaken by the R-PAC Project aimed to integrate a palliative approach into this critical indicators flow chart (Figure 8-1) to enable the aged care team to more readily identify both the subtle changes experienced by residents overtime and to identify which of the three palliative care pathways were indicated, either: i) maintenance of a palliative approach; ii) specialist palliative care input to manage resident’s complex care needs; iii) or end-of-life care\(^\text{21}\).
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New models of care are required to meet the palliative care needs of older people in the aged care setting\(^{14}\). The delivery of a palliative approach in residential aged care in regional Australia is affected by a multitude of factors on a number of levels that need to be taken into consideration when developing a model of care. Although there is no universally accepted definition, a ‘model of care’ is a term generally used to describe a multi-dimensional concept that explains the manner by which health care is provided\(^{51}\). Davidson and Elliott\(^{52}\) suggest that a model of care is a conceptual tool that is ‘a standard or example for imitation or comparison, combining concepts, belief and intent that are related in some way’ (p. 121). They propose that the essential elements of any model of care should:

\[
\text{...be evidence-based and/or grounded in theoretical propositions; be based upon assessment of patient and health provider needs; incorporate evaluation of health related and intervention outcomes; be inclusive of consultation with key stakeholders; be considerate of the safety and wellbeing of}
\]

(f) What are the key components of a sustainable model of care, to facilitate the delivery of a palliative approach to the end-of-life care for older people in residential aged care within this regional community?

Figure 8-1: Flow chart to facilitate appropriate palliative care pathways in aged care

Source: Adapted from Kessler et al\(^{50}\) (p. 53)
nurses; involve a multidisciplinary approach where applicable; consider the optimal and equitable utilisation of health care resources; optimise equity of access for all members of society; include interventions that are culturally sensitive and appropriate\(^{(52)}\) (p. 123).

A model of care is an overarching design for the delivery of a particular type of health care that is underpinned by a theoretical basis, best evidence based practice and accepted standards\(^{(53)}\). Having an agreed model of care helps to ensure that all health care providers are working towards commonly goals and are able to evaluate their performance on a mutually agreed basis\(^{(53)}\). The insights gained from the R-PAC Project suggest that developing a sustainable model of care to facilitate the delivery of a palliative approach in residential aged care will need to address a range of diverse factors at three distinct levels: i) consumers, ii) health care organisations; and iii) policy.

**Consumers**

At the micro level the focus is on the health care needs of the resident and their family\(^{(54)}\). The family includes the residents’ legal guardian or the person who has a close, continuing relationship with the resident\(^{(55)}\). Any model of care that is developed needs to address the increasing frailty, co-morbidities, psychosocial needs and increased vulnerability of older people dying in the aged care sector\(^{(14)}\). It requires the active input of residents and their families into the reform process, acknowledges the central role of the general practitioner in care planning and delivery and needs to consider care team role delineation.

**Health Care Organisation**

At the meso level the focus is on the health care organisations that facilitate the delivery of health care\(^{(54)}\). In Australia, this includes: general practices, residential aged care facilities, acute health care services and community based allied health providers. This mix of both public and private organisations and providers involved in aged care provision adds to the complexity of care delivery and reform.

**Policy**

At the macro level the focus is on the policy environment in which the values, principles and strategies for aged care services are developed and the decisions about resource allocation are
determined\textsuperscript{(54)}. The Commonwealth Aged Care Act sets out the legal framework for the delivery of care to older people in the residential aged care sector\textsuperscript{(30)}. Under this Act the independent Aged Care Standards and Accreditation Agency has been established to manage the aged care accreditation process\textsuperscript{(56)}. This Agency also provides accreditation support, information and education to the aged care sector\textsuperscript{(56)}.

The education of the aged care workforce is the responsibility of numerous educational institutions ranging from the schools of nursing, medicine and allied health in the university sector, Colleges of Technical and Further Education along with providers of post basis continuing professional development packages, who are registered training organisations. In acknowledging the importance of tertiary education as a lever for change in the aged care setting\textsuperscript{(57)}, a range of Commonwealth funded scholarships have been developed to promote the uptake of tertiary education by aged care and rural nurses\textsuperscript{(58)}.

Palliative Care Australia as a peak non-government organisations was contracted by the Commonwealth in 2005 to 06 to promoted awareness of the palliative approach guidelines amongst aged care personnel\textsuperscript{(59)}. The Commonwealth also funded the Community Services and Health Industry Skills Council to develop two palliative approach competency units\textsuperscript{(60)}. These elective units can be completed by people undertaking Certificate III and IV qualifications in aged care work or home and community care\textsuperscript{(60)}. Palliative Care Australia was subsequently commissioned to develop teaching resources for the two palliative approach units focusing on the delivery of a palliative approach in the aged care sector\textsuperscript{(59)}. Both of these interventions will help to integrate a palliative approach into care assistants’ training. At the time of the R-PAC Project the continuing professional development needs of registered nurses and general practitioners to facilitate a palliative approach had yet to be systematically addressed.

\section*{8.3 Conceptual framework}

Both Wagner’s Chronic Care Model\textsuperscript{(61-63)} (Figure 8-2) and the WHO Innovative Care for Chronic Conditions Framework\textsuperscript{(61)} (Figure 8-3) were adopted to guide the development of the proposed model of care for residential aged care. These conceptual frameworks suggests that achieving health care reform requires a strategic approach addressing system, patient and provider issues\textsuperscript{(22)}. This model has been used by a diverse range of health care organisations to improve health care delivery to people with chronic and complex illnesses\textsuperscript{(54, 61, 64, 65)}. As the majority of people in residential aged care have these conditions, it was considered that
this approach would have utility as an organising framework for the model of care development.

Figure 8-2: Wagner’s Chronic Care Model

Source: Wagner\textsuperscript{(64)}
8.4 Characteristics of the proposed Model of Care

Several key components essential to model of care development have been identified from the findings of the investigations comprising the ‘Residential - Palliative Approach Competency Project’ (Figure 8-4). Importantly, older people with non-malignant disease residing in aged care facilities have different palliative care needs compared to people with cancer, who are the traditional recipients of palliative care. People admitted to residential aged care facilities tend to have a higher incidence of chronic and complex diseases, experience multiple health problems over an extended period of time, have more communication problems and are more likely to have an unpredictable time of death. The protracted decline associated with these chronic and complex illnesses means that older people have specific palliative care needs that ought to be addressed well before they reach the terminal phase of their illness. Integrating a palliative approach from a resident’s admission into aged care would help to ensure that: the myriad of symptoms experienced
Residents don’t go under assessed and under treated\(^{(21)}\); and that the unique needs of older people who experience communication problems due to disability or dementia are better acknowledged and catered for\(^{(6)}\).

**Figure 8-4**: P-PAC Project’s proposed Model of Care

Models of care promoting team interaction and integrating appropriate support mechanisms are also critical, especially within the context of population ageing\(^{(22, 25)}\). Collaborative partnerships across care settings need to be established and supported to facilitate the effective delivery of a palliative approach for older people with complex care needs. In addition, developing a sustainable model of care will require the integration of a rehabilitation philosophy within a palliative approach paradigm to balance older peoples’ curative and palliative needs over an extended period of time. Achieving this will help to maximise older peoples’ independence whilst minimising their discomfort and distress\(^{(68)}\).

Attaining this ideal in the Australian aged care sector requires: a commitment to ongoing consumer involvement in all change processes\(^{(69-71)}\); an adequately prepared workforce with the pre-requisite gerontology, palliative care competencies and communication skills. It also
requires a commitment to maintaining adequate skill mixes in residential facilities\(^{(72, 73)}\); active general practitioner input into care planning\(^{(25, 29)}\) and adoption of collaborative multidisciplinary care planning processes to ensure that residents, their families and general practitioner and aged care personnel all share in decision making.

### 8.4.1 Enhancing the positive policy environment

In the context of population ageing, maintaining a positive policy environment is a critical factor to improving the delivery of care to older people in residential aged care. Recently, in Australia a series of new policies has fuelled a range of aged care reforms\(^{(21, 74)}\). Although, these are important developments additional reform is indicated in the areas of health policy and funding models that further promote the delivery of a palliative approach in residential aged care. Previously, Australia’s aged care policies had a significant focus on rehabilitation\(^{(75)}\) and this focus may have previously acted to limit the recognition that palliative care is required to better meet the needs of residents who have high levels of disability, discomfort and often distress\(^{(6)}\). The emergence of a palliative approach is an important development towards narrowing the gap between rehabilitation and palliative care. However, best practice evidence cannot be translated into action if it is not enabled by appropriate health policies\(^{(76)}\).

Mechanism for funding Australian aged care facilities needs to more accurately reflect their role as slow stream hospices for the frail aged. An aged care funding instrument that is sensitive to a residents’ need for a palliative approach, specialist palliative care review or end-of-life care, is indicated. This funding formula needs to also capture the degree to which residents require access to timely and effective palliative care based upon the severity, duration, urgency and the scope of services required to address their specific palliative care needs\(^{(20)}\).

As previously discussed, the Aged Care Act\(^{(30)}\) shapes the delivery of care to older people from a legislative perspective. This was evident in the R-PAC Project, which found that much of the documentation in residents’ notes was driven by the Residential Classification Scale funding tool\(^{(77)}\), as opposed to clinical need. Separating nursing documentation from the aged care funding tool would help better address residents’ actual care needs in accordance with best evidence based care\(^{(78)}\). This change would also allow for more appropriate palliative care clinical assessment and end-of-life care planning tools to be routinely utilised\(^{(11, 22, 26, 35)}\).
Ideally, all residents should be able to choose their general practitioner. However, a shortage of doctors, time constraints, distance and workload make it difficult for many general practitioners in regional Australia to undertake regular visits to residential aged care facilities\textsuperscript{(25, 29)}. A more pragmatic approach to providing medical care for older people in residential aged care needs to be considered and negotiated. In addition, health policy changes are required to ensure there is adequate remuneration and reimbursement to secure general practitioner and other health care provider input to care, as required. The barriers noted in this study towards advance care planning require further investigation. A new Medicare item\textsuperscript{(79)} maybe required to reimburse general practitioners for undertaking these often lengthy and emotional discussions with residents and their families.

\textbf{8.4.2 Engaging health care organisations}

Aged care nurses play an important role in the decision making process\textsuperscript{(80)}. Based on the R-PAC Project’s findings and a review of the literature it is evident that residents’ palliative care needs will be effectively managed if there are: i) appropriate systems in place; ii) aged care nurses, care assistants and general practitioners with palliative care competencies; iii) clearly defined goals of care; and iv) the necessary resources for the delivery of best evidence based symptom management\textsuperscript{(23, 24, 26, 81-83)}.

A collaborative approach to care has been identified as being of critical importance to an integrated health care system\textsuperscript{(39, 84-86)}. Successful integration will only occur if all parties, consumers and relevant health care providers actively participate in planning and implementation\textsuperscript{(20)}. There are several options that could potentially facilitate the integrated care that is essential for the delivery of a palliative approach. The establishing of a pre-admission style clinic would enable a palliative approach to care to be outlined to all prospective residents and their family\textsuperscript{(11)}. This initiative has the potential of setting the scene, and shaping expectations, while guiding and informing aged care personnel about the resident’s care needs and wishes and family’s expectations. This pre-admission clinic would provide an ideal forum to negotiate and document the resident’s advance care plan and in the process help to integrate it as a component of routine care planning. Actively promoting a palliative approach would help to ensure that residents and their families were cognisant of the meaning and implications of this type of care and help to create a more permissive environment for exploration of issues related to end-of-life care preferences, death and dying\textsuperscript{(11, 27)}. 

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Systematic mechanisms are required to engage all relevant health care providers in care planning\(^{(87)}\). Regular multidisciplinary case conferencing would assist in embedding a palliative approach as this forum would facilitate collaborative care planning, help identify when residents required specialist palliative care input and assist with the coordination of end-of-life care\(^{(19, 85)}\). Adopting this process would help ensure that symptoms were identified and treated, and provide an opportunity to actively engage residents and their families in the clinical decision making. Multidisciplinary case conferencing also offers action learning opportunities. This forum would provide aged care personnel and general practitioners with a supportive group structure to facilitate learning through actions and assist with the identification of strategies to overcome clinical problems\(^{(84, 88, 89)}\).

The R-PAC Project findings have important implications for the residential aged care workforce. Despite the diverse skill mix in residential aged care being a well recognised factor\(^{(46)}\), the large representation of unregulated workers has several implications for delivering a palliative approach. This observation underscores the importance of maintaining a significant proportion of registered nurses in the residential aged care workforce for effective management of palliative care issues\(^{(37)}\). It also highlights the critical importance of palliative care knowledge and skill and recognises that this be tailored to meet the specific learning needs of each discipline involved in the provision of care to older people\(^{(23)}\).

The high proportion of women employed in the aged care workforce, begs exploration of issues in relation to status and power and wage parity. Given the relationship between knowledge and power\(^{(90)}\), the issue of status for residential aged care workers needs to be addressed at a professional level. Achieving wage parity, recognising aged care as a nursing specialty and establishing advanced practice nursing roles within residential aged care facilities\(^{(91-93)}\) are likely to be important drivers. A failure to recognise the value of aged care professionals sends a message to the community that as a society we don’t value older people and that the acute care environment is the preferred site for quality care, particularly at the end-of-life\(^{(11)}\). The importance of recognising aged care as a specialty is of increasing importance.
8.5 Recommendations for model implementation

8.5.1 Palliative approach to underpin all future residential aged care policy

Policy initiatives are fundamental to making long-term system changes that can result in improvements in access, quality and cost of care for older people\textsuperscript{(76)}. Policy makers need to ensure that a palliative approach underpins all future residential ageing polices and funding formulas to embed the delivery of best evidence based care for older people living in Australian aged care facilities\textsuperscript{(94)}.

8.5.2 Active consumer engagement in reform

Exploring the needs, attitudes and values of older people towards end-of-life care will help shape the establishment of more appropriate aged care systems at a both a national and local organisational level\textsuperscript{(14)}. Engaging consumers in this process of funding and policy reform is required to ensure that there is more effective commissioning of care for the frail aged.

8.5.3 Creation of multidisciplinary care teams

The complexity of residents’ care needs dictates that an individualised multidisciplinary team is required to address the specific care needs of each resident. In the aged care sector the multidisciplinary team is likely to consist of a combination of aged care, health and social welfare disciplines\textsuperscript{(21)}. Establishing multidisciplinary teams requires a commitment to effective team work, collaboration and communication, which is facilitated by the development of appropriate systems and process\textsuperscript{(85)}. Multidisciplinary care ensures the provision of evidence based care in accordance with agreed guidelines and active involvement of residents and their families into care decisions\textsuperscript{(85)}. Engaging in multi professional learning opportunities at an undergraduate and postgraduate level will likely facilitate multi disciplinary care.

8.5.4 Recognition of aged care as a speciality

The increased demand for aged care staff is occurring at a time when there is a global shortage of nurses\textsuperscript{(76)}, the aged care workforce itself is ageing\textsuperscript{(46)} and there are challenges recruiting new nursing graduates into the speciality\textsuperscript{(78)}. If aged care nursing is to become an attractive career option it needs to be recognised as a speciality that requires both
gerontological and palliative care competencies, has its own credentialing processes, and offers appropriate remuneration and defined aged care clinical career pathways.

8.5.5 Integrating aged and palliative care practice into the curriculum

There is a need to integrate aged and palliative care principles across all areas of the nursing, medical and allied health curricula, particularly within a context of population ageing\(^{(95)}\). In addition, the diversity of the workforce highlights the need for a coordinated approach to the development of continuing professional development palliative approach packages for aged care nurses and care assistants. These learning packages also need to be readily available to aged care personnel.

8.6 Recommendations for future research and nursing practice

Addressing a palliative approach in non-malignant conditions, particularly within the residential aged care sector is a fertile area for future research. Exploring a range of issues related to instrumentation, outcome measures, educational interventions and models of care are of particularly priority. Currently, many of the instruments used in palliative care have had items generated from a malignant paradigm of death and dying. Yet, the data that are demonstrated in the R-PAC Project, in addition to the findings of other investigators confirms a very different illness trajectory for older people dying from non-malignant disease\(^{(26, 33)}\). For many residents their symptom manifestations were subtle and not dramatic, which may have limited the degree to which these symptoms were assessed. This finding reinforces the importance of empirical assessment to give older people a voice, particularly those with cognitive impairment\(^{(26)}\). This finding also compels researchers to develop a range of alternative process and outcome measures that are more sensitive to measuring the needs of older people dying in the residential aged care setting.

Further, a range of issues have emerged from the R-PAC Project that have been resistant to change and clearly need further investigation. Of note, the issue of advance care planning and not for resuscitation orders are inherently problematic within the aged care sector. It is likely that a complex interplay of individual values and beliefs, as well as policy, legal and regulatory issues are all conspiring to limit the exploration and documentation of residents’ end-of-life care preferences in a systematic manner\(^{(96)}\).
8.7 Sustainability strategies

There is compelling evidence at the completion of the R-PAC Project that there is a dynamic, collaborative and enabling culture within the Coffs Harbour residential aged care community. This is clearly evident in several partnership initiatives that will ensure the sustainability of many components of the R-PAC Project’s multifaceted intervention.

8.7.1 Securing additional competitive funding

At a National level additional palliative care funding was made available through three competitive grant process during late 2005/06 under the ‘Strengthening Cancer Care’ measure\(^97\). The funding was designed to help local groups, church and charitable hospices and aged care personnel to better provide support to people requiring palliative care and their families. Approximately $730,000 has been secured locally to enable several of the R-PAC Project initiatives to be sustained until June 2009. The first round of local palliative care grants programs funds were made available to provide equipment and to fit out premises\(^97\). One local aged care provider secured funding to purchase palliative care equipment, including: syringe drivers, an oxygen concentrator and high low bed and to fit out a room for end-of-life care valued at approximately $100,000. This was critical funding for an aged care facility caring solely for people with high care needs in an older facility without any single rooms. During Round Two, funding of $130,000 was secured to enhance the spiritual care competencies of local health care providers, with a discreet arm focussing on the needs of aged care personnel\(^97\). During Round Three, two separate care planning projects were funded, with each being allocated approximately $250,000, which will ensure the sustainability of a range of R-PAC Project initiatives\(^97\). One project will focus on further embedding the multi-agency, multidisciplinary specialist palliative care team meetings, so that aged care personnel will continue to have access to this specialist care planning forum. This project will also continue to establish multidisciplinary case conferencing within the aged care setting to ensure that this type of forum is operational with all local aged care facilities. The second care planning project funding was allocated to a large aged care provider and this project is focussing on: establishing multidisciplinary case conferencing in three residential aged care facilities and further embedding a palliative approach through ongoing learning and development initiatives and policy reform. In keeping with an integrated approach to care, these two separate projects have engaged in a collaborative
partnership to sustain the link nurse initiative and care assistant palliative approach competency workshops and plan to target the learning needs of registered nurses in aged care.

8.7.2 Palliative approach pamphlet

At the end of the third phase of R-PAC Project action research process it emerged that aged care personnel desired to have promotional material to give to prospective residents and their families detailing a palliative approach. A consultative process was undertaken with aged care personnel, residents and their families to further develop this concept. This resulted in the collaborative development of a palliative approach pamphlet with the Woolgoolga ‘Life After Placement Group’ (Appendix 14). This pamphlet has since been made available to all local residential aged care facilities and the palliative and aged care assessment team.

8.7.3 Collaborative methodology

At the end of the R-PAC Project the Critical Reference Group acknowledged that, despite the positive gains had been made, there was still scope to enhance pain assessment, particularly for people with cognitive impairment, increase advance care planning and trial the use of an end-of-life care pathway for use in aged care\(^{26}\). Coincidentally, at the same time national funding through the Best Practice Aged Care Grants to promote evidence based care in residential aged care was announced\(^ {32}\). A funding proposal that built upon the R-PAC Project initiatives in the nine aged care facilities and utilised Collaborative Methodology was developed and submitted for consideration.

Collaborative methodology was chosen for this proposal as it has been demonstrated to be effective in implementing changes across organisations to reduce the gaps between what is known and practiced\(^{98-100}\). It was also considered that it would provide an opportunity to extend the intervention beyond education initiatives, which alone rarely results in sustained organisational change. Collaborative methodology offered the potential of dismantling much of the traditional patterns of care which exist in the aged care sector by promoting new practices based on best available evidence and developing clinical leaders\(^ {101}\). This approach would provide ongoing leadership and support to participating aged care facilities to enable them to utilise the plan-do-study-act continuous improvement cycle to further develop and embed the process and systems required to address the delivery of a palliative approach to care for residents. A model of change management tailored to address the palliative needs of residents and reconfigure delivery systems to increase the uptake of evidence based
management would be integral to this approach. This Collaborative aims to increasing pain assessment, advance care planning and improve the management of end-of-life symptoms by 80%. This will be achieved by harnessing existing drivers for practice change that operate in the aged care sector, including: Residential Classification Scale, quality improvement initiatives, education processes and multidisciplinary care. The engagement of clinical leaders, executive support, structured timelines, reporting mechanisms, implementation of evidence based strategies and sharing of knowledge are key elements of this proposal.

A new Aged Care Funding Instrument is expected to shortly replace the current Residential Classification Scale as the mechanism for determining the Government subsidy provided to each aged care facility, this is unlikely to impact adversely on this proposed model\(^{\text{102}}\). If anything, this instrument is expected to ensure a better match between care needs and funding. It is also anticipated that this instrument will reduce the need for excessive documentation created by aged care providers to justify funding.

An important element of this proposal was the recognition by the Critical Reference Group for the inclusion of residents and family members in the Collaborative Action Teams to be established in each participating aged care facility. These teams would provide the structure to enable residents and their families to have input into the development and implementation of the palliative approach collaborative at a local level. Consumer engagement is critical to effective health system reform\(^{\text{20}}\).

### 8.8 Reflections on the study process

The strengths and limitations of the R-PAC Project’s action research processes and mixed methods design have been well described in the preceding chapters. Many of these issues are in fact a two edge sword, with both strengths and limitations. The potential criticism in the lack of methodological rigour relating to issues such as sampling, are in fact some of the key strengths of action research process. Throughout the R-PAC Project, close attention was paid to methodological rigour and conceptual coherence. The principles of consultation, participation and empowerment were closely observed during the Project design, implementation and analysis. The benefits of this approach in terms of empowerment and capacity development are reflected in the study findings. The fact that the R-PAC Project initiatives have secured ongoing funding and continue, even since the researcher has left the project setting are testimony to the utility of the action research process.
There are some shortcomings of the R-PAC Project that are useful to consider in the interpretation of the study findings. Firstly, as in accordance with the action research process this project was contextually bound and therefore extrapolation of the interventions trialled in this study to other settings must be considered with these caveats. Secondly, the participants in this study were primarily of Anglo-Celtic origin, reflecting the demographics of the NSW Mid North Coast\(^7\), \(^{103}\) and therefore not reflective of the cultural diversity of contemporary Australia or the aged care workforce\(^{46}\). Thirdly, the high representation of not-for-profit residential aged care settings may preclude implementation of the intervention in organisations with a more profit driven philosophy. Fourthly, the absence of the views of patients and their families is an omission of this study. The issues of patients and families were not addressed directly because the Critical Reference Group wanted to defer this issue to a future time, potentially reflecting the groups’ lack of confidence at the commencement of the project and their desire to initially focus on up skilling aged care personnel. Of interest, as the R-PAC Project was drawing to a close the Critical Reference Group had determined that the needs of residents’ and their families required further exploration and this is the current focus of the nine residential aged care facilities, which is reflected in the Best Practice Grant application. It is also important for people interested in implementing this model of intervention to be cognisant of the fact that the R-PAC Project had access to considerable funding and an overarching local mandate to strengthen palliative care partnerships, both of which were significant enabling factors.

The R-PAC Project was characterised by lower than expected numbers of registered nurses in some facilities participating in the R-PAC Project’s learning and development strategy. This reflects issues of recruitment, as well as transience and attrition of participants. It may also reflect the educational beliefs of this cohort of aged care personnel, who tend to be older, with many nearing retirement. Alternatively, these participation rates may have been due to the registered nurses accessing in-house palliative care education sessions arranged by the link nurse within their facility. The absence of a mechanism to measure the degree to which this occurred combined with an evaluation of the effectiveness of the peer education delivered by the link nurses in the nine residential aged care facilities is a limitation of this study. The offer of attaining credit points towards a graduate diploma in palliative care was included as an incentive for link nurse participation and to subsidise the costs associated with higher education. In hindsight, as only two link nurses took up this offer, higher educational attainment may not be a significant driver for this cohort, but this requires further investigation.
CHAPTER EIGHT

CONCLUSION

Using this research approach with its absence of a control group, the heterogeneity of the intervention and the presence of a large number of extraneous variables has limited the extrapolation of findings to other settings. These factors have also impeded the ability to confirm whether any observed improvements were directly attributable to the intervention. The R-PAC Project has endeavoured to mitigate against these limitations by measuring overall changes in nurses’ and care assistants’ palliative care competencies and confidence by administering ‘Tool 2.1: Palliative care providers’ views and attitudes’ during Phase One (Time 1) and at the conclusion of the project in Phase Four (Time 2). Action research is a post positivist research method and as such, it was not considered appropriate to adopt a positivist research design. The decision not to use a code precluded linking the Time 1 and Time 2 participants and was in keeping with the philosophy underpinning action research. However, this decision has limited this study’s ability to determine the impact of the multifaceted intervention. A positive design using paired test would have provided more meaningful data, but this was at odds with an action research approach.

Similarly, the focus groups were conducted during Phase One to collect baseline data (Time 1) and repeated after the intervention to measure perceived changes during Phase Three (Time 2). While the retrospective chart audit data was not intended to ascribe causality, it was used to identify trends, generate hypotheses and provide a greater insight into the end-of-life care provided in the nine residential aged care facilities at two points in time: at baseline (Time 1) and prior to the study’s commencement and following the implementation of the intervention (Time 2). In addition, end-point data such as the number of deaths managed within the facility are seen as surrogates for aged care nurses’ and care assistants’ palliative care confidence to manage resident’s deaths and have been used as outcome data.

Although, in hindsight the use of collaborative methodology at the outset of the R-PAC Project may have helped secure greater organisational change, it is doubtful whether aged care personnel would have had the confidence to agree to this type of approach at the commencement of the project. The use of action research has allowed for the full exploration of issues identified to be of most concern to aged care personnel and actively engaged them in a process of change in which they set the tempo and direction. It used an approach that built confidence by valuing and validating the age care providers’ role and empowering them to undertake the changes required to enhance palliative care delivery. The emancipating process of the action research method combined with a population focus has allowed for the
strengthening of local care partnerships that will be better able to endure the rigours of a more rapid change process driven by the Collaborative Methodology planned for the future.

### 8.9 Strengths of the study approach

Despite these limitations, the R-PAC Project has some notable innovations and strengths in facilitating the delivering of a palliative care approach in residential aged care. Firstly, this project has characterised the Australian aged care population in greater depth and explored the use of outcome measures in the study setting. Secondly, this project has successfully engaged a range of aged care personnel and captured 100% participation of residential aged care facilities in a regional community. To our knowledge this is the first time that this level of participation has been achieved on a population basis.

Thirdly, the action research method has facilitated and enabled a cascade of engagement, participation and practice innovation. Critical reflection throughout the R-PAC Project has ensured that numerous lessons have been noted and incorporated into subsequent actions. One of the key lessons to emerge is that an action research approach can inspire people through optimism and action. Its ability to actively and effectively engage all levels of health care providers as partners in health care reform has been one of the R-PAC Project’s critical success factors. This approach also allowed for the acknowledging and validating of the role of all aged care personnel; it facilitated health care providers’ sharing of valuable insights into usual practice and engaged them in developing practical solutions to identified problems. Collaboratively addressing these problems secured a series of small wins that helped create an empowering environment and the belief that positive change was possible. Fourthly, the study has strong evidence of internal coherence in respect of method as demonstrated by the level of participation of collaborators and the successes of the project over time. Fifthly, the use of mixed methods embedded within a framework of action research has enabled the derivation of a rich and lucrative data set that has not only informed the study progress from a range of perspectives but will also inform future policy, clinical practice and research.

### 8.10 Conclusion

The ‘Residential - Palliative Approach Competency Projects’ use of mixed methods has demonstrated the effectiveness of action research in engaging aged care personnel in a change process aimed at embedding a palliative approach in residential aged care. It has provided valuable insights into how to improve the delivery of palliative care with the findings from the
sub-studies being used to drive the action research process and forming the basis of the proposed model of care. This model of care acknowledges that death is an expected and natural conclusion for older people living in residential aged care and challenges policy makers and health care planners to ensure that a palliative approach underpins all future aged care policy development. Sustaining a culture that is committed to ongoing learning and development interventions is critical to embedding a palliative approach into everyday aged care practice. Adopting a multidisciplinary approach to care planning and delivery will ensure that the needs of residents and their families are adequately addressed. Achieving this will help to ensure that the same high standards of care delivered by specialist palliative care services are afforded to all older people in the Australian aged care setting. The successful integration of a palliative approach into all Australian residential aged care facilities requires policy makers to adequately fund, resource and support this sector to embrace this model of care. Committing and implementing these reforms will ensure that people who live and die in Australian residential aged care facilities and their families are proved with care that is grounded in comfort and dignity and based on the best available evidence.
8.11 Reference list


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Appendix 1.

LETTERS OF SUPPORT
Dr Michael Darcy  
Associate Dean for Research  
College of Social and Health Sciences  
University of Western Sydney  
PO Box 1797  
Penrith DC. NSW

Dear Dr Darcy,

Re: Letter of support for application of Jane Phillips to upgrade from Masters Honors to PhD

This letter is to document the support of the Director, Palliative Care Section, Rural Health and Palliative Care Branch, Health Services Improvement Division, Australian Government Department of Health and Ageing for Jane's project, Residential – Palliative Approach Competency Study (R-PAC). This project sits under the umbrella of the national Rural Palliative Care Project but has been derived independently by Jane in consultation with the local project and coordinating teams. This project has been conceived and developed by Jane.

I am very encouraged by Jane's decision as capacity development is a key strategy of the Rural Palliative Care Project. I enthusiastically endorse this project and recognise that the outputs of the Residential – Palliative Approach Competency Study (R-PAC) will represent Jane's intellectual property and fulfill the criteria for PhD. I have been told by A/Prof Davidson that the funding source will be acknowledged in publications and reports. The choice of an Action Research Framework will have strategic gains more broadly for the Mid North Coast Project.

Please do not hesitate to contact me should you require further information,

Yours sincerely,

[Signature]

Rita Evans  
Director, Palliative Care Section,  
Rural Health and Palliative Care Branch,  
Health Services Improvement Division  
5 August 2004
13 August 2004

Dr Michael Darcy
Associate Dean for Research
College of Social and Health Sciences
University of Western Sydney
PO Box 1797
Penrith DC, NSW

Dear Dr. Darcy,

Re: Letter of support for application of Jane Phillips to upgrade from Masters Honours to PhD

This letter is to document the support of the Mid North Coast Division of General Practice for Jane's project, Residential - Palliative Approach Competency Study (R-PAC). This project sits under the umbrella of the national Rural Palliative Care Project but has been derived independently by Jane in consultation with the local project and coordinating teams. This project has been conceived and developed by Jane.

I am very encouraged by Jane's decision as capacity development is a key strategy of the Rural Palliative Care Project. I enthusiastically endorse this project and recognize that the outputs of the Residential - Palliative Approach Competency Study (R-PAC) will represent Jane's intellectual property and fulfill the criteria for PhD. I have been told by Dr. David Davidson that the funding source and Mid North Coast Division of General Practice will be acknowledged in publications and reports.

Please do not hesitate to contact me should you require further information.

Yours sincerely,

[Signature]

Dr. David Ellis
Chief Executive Officer

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PO Box 924, Suite 2, Level 1, Sydney House, Cnr Park Ave & Gordon Street, Cotts Harbour, NSW 2480.
Ph: 02 4922 1111 Fax: 02 4922 1144 Email: info@ncc.com

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Appendix 2.

*R-PAC Project Governance*
### R-PAC Project Governance

#### 1. Mid North Coast Division of General Practice – Rural Palliative Care Project Advisory Group

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged Care Professionals Group</td>
<td>Elected representative</td>
</tr>
<tr>
<td>Baringa Private Hospital</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>Coffs Harbour Private Nursing Service</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>Consumer Representative</td>
<td>Palliative care consumer</td>
</tr>
<tr>
<td>Galambila Aboriginal Medical Centre</td>
<td>Chief Executive Officer</td>
</tr>
<tr>
<td>Woolgoolga General Practice</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>Gordon Street General Practice</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>Mid North Coast Division of General Practice</td>
<td>Chief Executive Officer</td>
</tr>
<tr>
<td>Mid North Coast Division of General Practice</td>
<td>Chief Medical Advisor – General Practitioner</td>
</tr>
<tr>
<td>Mid North Coast Division of General Practice</td>
<td>Rural Palliative Care Project Coordinator</td>
</tr>
<tr>
<td>Mid North Coast Division of General Practice</td>
<td>Rural Palliative Care Project Nurse</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>General Manager</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>Medical Director</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>Manager Ambulatory Care</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>Manager Primary Health Care &amp; ACAT</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>CNC Aged Care Assessment Team</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>CNC Palliative Care</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>NUM Acute Medical Ward</td>
</tr>
<tr>
<td>Southern Cross University</td>
<td>Professor Aged Services Learning &amp; Research</td>
</tr>
<tr>
<td></td>
<td>Collaboration</td>
</tr>
<tr>
<td>University of NSW – Rural Medical School</td>
<td>Associate Professor Medicine – Coffs Campus</td>
</tr>
</tbody>
</table>

#### 2. Aged Care Professionals Group

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catholic Care of the Aged</td>
<td>Director of Care (January – September 2004)</td>
</tr>
<tr>
<td>Coffs Haven Aged Care Facility</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>Coffs Harbour Nursing Centre</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>Coffs Harbour Nursing Centre</td>
<td>Assistant Director of Nursing</td>
</tr>
<tr>
<td>Legacy Nursing Home</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>Legacy Nursing Home</td>
<td>Assistant Director of Nursing</td>
</tr>
<tr>
<td>Masonic Aged Care Facility</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>Mater Christi Aged Care Facility</td>
<td>Director of Care</td>
</tr>
<tr>
<td>Mater Christi Aged Care Facility</td>
<td>Assistant Director of Care</td>
</tr>
<tr>
<td>North Coast Area Health</td>
<td>CNC Aged Care Assessment Team</td>
</tr>
<tr>
<td>Oznam Villa Hostel</td>
<td>Hostel Manager</td>
</tr>
<tr>
<td>St Augustine’s Nursing Home</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>St Josephs Hostel</td>
<td>Hostel Manager</td>
</tr>
<tr>
<td>Woolgoolga and Districts Retirement Village</td>
<td>Director of Nursing</td>
</tr>
<tr>
<td>Waratah Respite Centre</td>
<td>Manager</td>
</tr>
</tbody>
</table>
### 3. R–PAC Project Critical Reference Group

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Position</th>
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</thead>
<tbody>
<tr>
<td>Residential Aged Care Facility 1</td>
<td>Assistant Director of Nursing</td>
</tr>
<tr>
<td>Residential Aged Care Facility 1</td>
<td>Care Assistant</td>
</tr>
<tr>
<td>Residential Aged Care Facility 2</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>Residential Aged Care Facility 3</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>Residential Aged Care Facility 3</td>
<td>Care Assistant</td>
</tr>
<tr>
<td>Residential Aged Care Facility 4</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>Residential Aged Care Facility 5</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>Residential Aged Care Facility 6</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>Residential Aged Care Facility 7</td>
<td>Assistant Director of Nursing</td>
</tr>
<tr>
<td>Residential Aged Care Facility 7</td>
<td>Care Assistant</td>
</tr>
<tr>
<td>Residential Aged Care Facility 8</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>Residential Aged Care Facility 9</td>
<td>Registered Nurse</td>
</tr>
</tbody>
</table>
Appendix 3.

R-PAC Project: HREC Approval
Dear Jane,

Re: HREC 05/060 Palliative Approach Competency Study

The Committee has reviewed your responses to the issues raised and the project mentioned above is now approved.

You are advised that the Committee should be notified of any further changes to the research methodology should there be any in the future. You will be required to provide a report on the ethical aspects of your project at the completion of this project. The form is located on the Research Services Web Page.

The Protocol Number HREC 05/060 should be quoted in all future correspondence about this project. Your approval will expire 30 December 2006. Please contact the Human Ethics Officer, Kay Buckley on tel: 02 49 360 863 if you require any further information.

The Committee wishes you well with your research.

Yours sincerely,

[Signature]

Professor Elizabeth Deane
Chairperson
UWS Human Research Ethics Committee
Co-Associate Professor Patricia Davidson
Appendix 4.

R-PAC PROJECT: INFORMATION SHEETS & CONSENT FORMS
APPENDIX 4

PALLIATIVE APPROACH

COMPETENCY STUDY

(“R-PAC Project”)

HEALTH CARE PARTICIPANT INFORMATION SHEET

The Palliative Approach Competency Study is a study being undertaken by Jane Phillips, PhD Candidate, University of Western Sydney which is focusing on the provision of palliative care within Residential Aged Care Facilities in Coffs Harbour, NSW. This study is a discreet arm of the Mid North Coast Rural Palliative Care Project, which is one of eight projects participating in the larger National Rural Palliative Care Program.

You are invited to participate in the Palliative Approach Competency Study. This Study would like to hear your views and assessments, based on your own experiences and knowledge regarding the provision of palliative care within local Residential Aged Care Facilities. You will have an opportunity to provide this valuable feedback by either participating in one of several planned focus group and/or by completing an anonymous questionnaire. Participating in the focus groups will take approximately one and a half hour’s, while completing a questionnaire is likely to take between 15 and 25 minutes. The results of both the focus groups and the questionnaires will be presented in an aggregated and summarised way and no details that might identify any individual participant will be made available.

If you are willing to provide feedback about your own views and experiences in this way, please sign the attached participation consent form. You may withdraw from the research at anytime if you wish. If you decide not to participate or to withdraw from participation, this will not affect your relationship with the Researcher, the Rural Palliative Care Program or your relationship with the University of Western Sydney.

If you would like further information, or have any questions about the Palliative Approach Competency Study please contact:

Ms Jane Phillips - PhD Candidate
Phone 0411 1106517
Email: jphilips@nurseandmidwifery.nsw.gov.au

Associate Professor Patricia Davidson
Phone 0414 674134
Email: patricia.davidson@hswh.nsw.gov.au

NOTE: This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Ethics Committee through the Research Ethics Officer: Tel: (02) 47 340 183. Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
HEALTH CARE PARTICIPANT INFORMATION SHEET

It is not expected that participation in the study will involve any risks or result in any harm or discomfort to you. However, if you feel you would like to talk to someone after completing the questionnaire or participating in a focus group, please contact the most appropriate person for you among the key contacts list detailed below.

Key Community Contacts

<table>
<thead>
<tr>
<th>Key Contacts</th>
<th>Address</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PhD CANDIDATE</strong>&lt;br&gt;JANE PHILLIPS</td>
<td>Mid North Coast Division of General Practice&lt;br&gt;PO Box 920&lt;br&gt;COFFS HARBOUR NSW 2430</td>
<td>02 6659 3652&lt;br&gt;041 1100 517</td>
</tr>
<tr>
<td><strong>A/Prof Trish Davidson</strong>&lt;br&gt;Academic Supervisor&lt;br&gt;-Ms Jane Phillips</td>
<td>Clinical Research Unit&lt;br&gt;School of Nursing, Family and Community&lt;br&gt;University of Western Sydney and Western Sydney Area Health Service&lt;br&gt;Health Building 59&lt;br&gt;ANECH Cumberland Hospital&lt;br&gt;5 Fleet St&lt;br&gt;PARRAMATTA NSW 2150</td>
<td>02 88382651&lt;br&gt;041 467 134</td>
</tr>
<tr>
<td><strong>North Coast Area Health Service Palliative Care Team</strong></td>
<td>North Coast Area Health Service&lt;br&gt;Coffs Harbour Health Campus&lt;br&gt;Locked Bag 812&lt;br&gt;COFFS HARBOUR NSW 2450</td>
<td>02 66 55 7675</td>
</tr>
<tr>
<td><strong>North Coast Area Health Service Aged Care Assessment Team</strong></td>
<td>North Coast Area Health Service&lt;br&gt;Coffs Harbour Health Campus&lt;br&gt;Locked Bag 812&lt;br&gt;COFFS HARBOUR NSW 2450</td>
<td>02 66 55 7633</td>
</tr>
</tbody>
</table>
PALLIATIVE APPROACH

COMPETENCY STUDY

("P-PAC Project")

Conducted by Jane Phillips – PhD Candidate
School of Nursing, Family and Community, University of Western Sydney

PARTICIPANT CONSENT FORM FOR

SERVICE PROVIDER/ COMMUNITY PARTICIPANTS

1. I ____________________________ consent to my involvement in the above study.

2. I understand that I am free to withdraw my participation in the research at any time, and if I do I will not be subjected to any penalty or discriminatory treatment.

3. The purpose of the research has been explained to me, including the (potential) risks/discomforts associated with the research. I have been given the opportunity to ask questions about the research and received satisfactory answers.

4. I permit the investigators to make audio-tape recordings as part of this project.

5. I understand that any information or personal details gathered in the course of this research about me are confidential and that neither my name nor any other identifying information will be used or published without my written permission.

6. By signing below I am indicating my consent to participate in the Palliative Approach Competency Study conducted by Jane Phillips, PhD Candidate, University of Western Sydney, as it has been described to me in the information sheet and in discussion with the researcher. I understand that the data collected from my participation will be used to evaluate the provision of palliative care within local Residential Aged Care Facilities and I consent for it to be used for that purpose.

SIGNED _________________________

NAME _________________________

(BLOCK LETTERS)

DATE _________________________
Appendix 5.

STUDIES B & H:

CHART AUDIT TOOL
Modified Liverpool End-of-Life Care Base Audit Tool

AUDIT NUMBER: 

CHART REVIEW DATE: __/__/_______ REVIEWER: ______________________

CENTRE NAME: ______________________ HOSPITAL: 1 HOME 2 RACF 3

DOB: _______/_____/_______ GENDER: Male 1 Female 2

ADMISSION DATE: __/__/_______ DEATH DATE: _______/_____/_______

DIAGNOSIS

<table>
<thead>
<tr>
<th>12. Primary Diagnosis</th>
<th>Select One</th>
<th>13. Secondary Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malignancy</td>
<td>1</td>
<td>Malignancy</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>2</td>
<td>Cognitive impairment</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>3</td>
<td>Cardiovascular</td>
</tr>
<tr>
<td>Respiratory</td>
<td>4</td>
<td>Respiratory</td>
</tr>
<tr>
<td>Neurological</td>
<td>5</td>
<td>Neurological</td>
</tr>
</tbody>
</table>

DO NOT FOR RESUSCITATE (DNR) ORDERS

20. Documented DNR orders? □ 1 Yes □ 2 No □ 3 No data
21. Scope of the DNR order defined and documented? □ 1 Yes □ 2 No □ 3 No data
22. Documentation of discussion DNR order with patient □ 1 Yes □ 2 No □ 3 No data
23. Documentation of discussion DNR order with family □ 1 Yes □ 2 No □ 3 No data
24. If DNR not discussed, reason documented? □ 1 Yes □ 2 No □ 3 No data
25. Documented advance care plan □ 1 Yes □ 2 No □ 3 No data
26. Evidence of advance care planning □ 1 Yes □ 2 No □ 3 No data

Please continue over the page

Source: Adapted from Ellershaw & Wilkinson (p.111)
### PHYSICAL CARE

#### 27. Classes of medication use 72 hours prior to death

- **Indicate with a ✓ Yes = □1  No = □2**

<table>
<thead>
<tr>
<th>System</th>
<th>Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alimentary system</td>
<td>Hyperacidity, reflux &amp; ulcers  Anti-spasmodic  Laxatives</td>
</tr>
<tr>
<td>Cardiovascular system</td>
<td>Antihypertensive  Beta blockers  Diuretics  Anticoagulants</td>
</tr>
<tr>
<td>Central Nervous System</td>
<td>Sedatives  Anti-anxiety agents  Antipsychotic agents  Antidepressants</td>
</tr>
<tr>
<td>Analgesics</td>
<td>Narcotics  Simple  Combination  Adjuvant analgesics</td>
</tr>
<tr>
<td>Musculoskeletal system</td>
<td>NSAID  Gout  Muscle relaxants</td>
</tr>
<tr>
<td>Endocrine</td>
<td>Insulin  Adrenal Steroid hormones  Pituitary hormones</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>Alkalizes</td>
</tr>
<tr>
<td>Infections</td>
<td>Antibiotics  Antifungal  Antiviral</td>
</tr>
<tr>
<td>Neoplastic disorders</td>
<td>Chemotherapy  Non-cytotoxic and supportive therapy</td>
</tr>
<tr>
<td>Respiratory system</td>
<td>Expectorants  Bronco spasm  Aerosols/inhalations  Anticholinergic</td>
</tr>
<tr>
<td>Other</td>
<td>Immunology  Allergic  Antihistamines  Eye  Ear, nose &amp; throat  Skin  Nutrition</td>
</tr>
</tbody>
</table>

#### 87. Total number of medications in use at 72 hours

[ ]

#### 88. Classes of medication use 24 hours prior to death

- **Indicate with a ✓ Yes = □1  No = □2**

<table>
<thead>
<tr>
<th>System</th>
<th>Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alimentary system</td>
<td>Hyperacidity, reflux &amp; ulcers  Anti-spasmodic  Laxatives</td>
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<tr>
<td>Cardiovascular system</td>
<td>Antihypertensive  Beta blockers  Diuretics  Anti-coagulants</td>
</tr>
<tr>
<td>Central Nervous System</td>
<td>Sedatives  Anti-anxiety agents  Antipsychotic agents</td>
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<tr>
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</tr>
<tr>
<td>Endocrine</td>
<td>Insulin  Adrenal Steroid hormones  Pituitary hormones</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>Alkalizes</td>
</tr>
<tr>
<td>Infections</td>
<td>Antibiotics  Antifungal  Antiviral</td>
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<td>Chemotherapy  Non-cytotoxic and supportive therapy</td>
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<td>Respiratory system</td>
<td>Expectorants  Bronco spasm  Aerosols &amp; inhalations  Anticholinergic</td>
</tr>
<tr>
<td>Other</td>
<td>Immunology  Allergic  Antihistamines  Eye  Ear, nose &amp; throat  Skin  Nutrition</td>
</tr>
</tbody>
</table>

#### 146. Total number of medications in use at 24 hours

[ ]

#### 147. Was the person still able to swallow at 72 hours?

- □1 Yes  □2 No  □3 No data  □4 Not indicated

#### 148. Was the person still able to swallow at 24 hours?

- □1 Yes  □2 No  □3 No data  □4 Not indicated

#### 149. Non-essentials medications discontinued at 72 hours?

- □1 Yes  □2 No  □3 No data  □4 Not indicated

*Please continue over the page*
### 150. The classes of drug ordered regular s/c during last 72 hours:

*Key: Classes of medications = MIMS Classification; Midazolam & Clonazepam = sedative, Lorazepam = anti-anxiety; Not indicated = No evidence of symptoms requiring therapy in notes*

- Analgesics
- Narcotics
- Central Nervous System
- Antianxiety
- Antipsychotic
- Sedatives
- Antiemetic
- Endocrine
- Adrenal steroid hormones
- Anticholinergic
- Other

### 161. The classes of drug ordered prn s/c during last 72 hours:

- Analgesics
- Narcotics
- Central Nervous System
- Antianxiety
- Antipsychotic
- Sedatives
- Antiemetic
- Endocrine
- Adrenal steroid hormones
- Anticholinergic
- Other

Were the following interventions discontinued in the last 72 hours?

- Blood Tests
- Antibiotics
- Intravenous Fluids
- Monitoring BSL
- Taking vital signs
- Artificial feeding

Please continue over the page
CARE PREFERENCE

178. Were instructions re: do not transfer to hospital documented? □1 Yes □2 No □3 No data
179. Was the patient’s care reviewed by the palliative care team? □1 Yes □2 No □3 No data
180. Was the patient’s care reviewed at a multidisciplinary team meeting? □1 Yes □2 No □3 No data
181. Was the family/person responsible involved in care planning? □1 Yes □2 No □3 No data
182. End Of Life Care Pathway commenced in last 72 hours? □1 Yes □2 No □3 No data
183. Seen by GP in last 72 hours? □1 Yes □2 No □3 No data

PSYCHOSOCIAL NEEDS

184. Patient aware of diagnosis? □1 Yes □2 No □3 No data
185. Patient aware s/he is dying? □1 Yes □2 No □3 No data
186. Family/person responsible aware patient is dying? □1 Yes □2 No □3 No data
187. Patients GP aware that patient is dying □1 Yes □2 No □3 No data
188. Patients plan of care discussed with family/others? □1 Yes □2 No □3 No data
189. Identified how family/others were to be contacted? □1 Yes □2 No □3 No data
190. Patients spiritual needs assessed? □1 Yes □2 No □3 No data
191. Patients spiritual goals identified? □1 Yes □2 No □3 No data

ONGOING ASSESSMENTS

Symptom assessment and management in last 72 hours

PAIN

| 192. | Did the patient have episodes of pain? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 193. | Was a standardised assessment tool used? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 194. | Was pain assessed every 4 hours/visit? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 195. | Was the patient given regular analgesics? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 196. | Were there episodes of uncontrolled pain? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 197. | Was break through analgesia given at this time? | □1 Yes □2 No □3 No data □4 Not Indicated |

NAUSEA AND/OR VOMITING

| 198. | Did the patient have episodes of nausea/vomiting? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 199. | Was a standardised assessment tool used? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 200. | Was nausea & vomiting assessed each shift/visit? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 201. | Were there episodes of nausea/vomiting? | □1 Yes □2 No □3 No data □4 Not Indicated |
| 202. | Was PRN antiemetic given at this time? | □1 Yes □2 No □3 No data □4 Not Indicated |

Pain: is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage”(2)(p.167).
### CONFUSION/DELIRIUM

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the patient have episodes of confusion/delirium?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was a standardised assessment tool used?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was confusion/delirium assessed each shift/visit?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Were there episodes of confusion/delirium?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was PRN antipsychotic given at this time?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
</tbody>
</table>

### RESTLESSNESS/AGITATION

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the patient have episodes of restlessness/agitation?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was a standardised assessment tool used?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Assessment of restlessness/agitation each shift/visit?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Were there episodes of restlessness/agitation?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Other possible causes considered?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was PRN sedation given at this time?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
</tbody>
</table>

### RESPIRATORY TRACT SECRETIONS

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the patient have episodes of excessive secretions?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was a standardized assessment tool used?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Assessment of secretions each shift?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Were there episodes of excessive secretions?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was PRN anticholinergic given at this time?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
</tbody>
</table>

### DYSPNEA

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the patient have episodes of dyspnoea?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was a standardized assessment tool used?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Assessment of dyspnoea shift/visit?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Were there episodes of dyspnoea?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was PRN narcotic given at this time?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was a prn anti-anxiety agent given at this time?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
<tr>
<td>Was oxygen therapy given at this time?</td>
<td>☐ Yes ☐ No ☐ No data ☐ Not Indicated</td>
</tr>
</tbody>
</table>
### GENERAL NURSING CARE, ASSESSMENTS OF:

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>226.</td>
<td>Mouth care 4 hourly?</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data</td>
</tr>
<tr>
<td>227.</td>
<td>Voiding problems each shift?</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data</td>
</tr>
<tr>
<td>228.</td>
<td>Indwelling Catheter used?</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data</td>
</tr>
<tr>
<td>229.</td>
<td>Incontinence aids used</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data</td>
</tr>
<tr>
<td>230.</td>
<td>Were pressure relieving devices used?</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data</td>
</tr>
<tr>
<td>231.</td>
<td>Regular pressure area care provided?</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data</td>
</tr>
<tr>
<td>232.</td>
<td>Wound care required?</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data</td>
</tr>
<tr>
<td>233.</td>
<td>Bowel care plan in place?</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data</td>
</tr>
</tbody>
</table>

### CARE AFTER DEATH

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>234.</td>
<td>GP contacted regarding patients death</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data ☐ 4 Not Indicated</td>
</tr>
<tr>
<td>235.</td>
<td>Post mortem discussed</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data ☐ 4 Not Indicated</td>
</tr>
<tr>
<td>236.</td>
<td>Special needs identified: religions/infection</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data ☐ 4 Not Indicated</td>
</tr>
<tr>
<td>237.</td>
<td>Family/others informed of tasks following death</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data ☐ 4 Not Indicated</td>
</tr>
<tr>
<td>238.</td>
<td>Appropriate documentation given to family/others</td>
<td>☐ 1 Yes ☐ 2 No ☐ 3 No data ☐ 4 Not Indicated</td>
</tr>
</tbody>
</table>

### THERAPEUTIC INTERVENTION SCORE

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.</td>
<td>Died before anything done</td>
</tr>
<tr>
<td>1</td>
<td>Comfort care (symptom control, social services, psychological support from nursing staff)</td>
</tr>
<tr>
<td>2</td>
<td>Moderate level care (Antibiotics, medications for chronic conditions, intravenous (IV) hydration, naso-gastric feeding, IV patient controlled analgesia)</td>
</tr>
<tr>
<td>3</td>
<td>High level care (Numerous medications for multiple active medical problems, blood transfusions, intrathecal medications)</td>
</tr>
<tr>
<td>4</td>
<td>Intensive level of care (Renal dialysis, ventilator assistance, hyper-alimentation, major surgery, intravenous vasopressors, intensive cardiac monitoring)</td>
</tr>
</tbody>
</table>

*Source: Adapted from Low and Kerridge*^{3}\(^\text{1}\), (p.380).

### REFERENCE LIST


Appendix 6.

STUDIES D & G:

SURVEY TOOL
TOOL 2.1: PALLIATIVE CARE PROVIDERS

About you

<table>
<thead>
<tr>
<th>Your sex</th>
<th>Male</th>
<th>Female</th>
<th>Your age</th>
<th>Your discipline:</th>
<th>Palliative care training (tick all that apply)</th>
<th>Specialist qualification</th>
<th>On the job training only</th>
<th>Short courses or other formal training not leading to a specialist qualification</th>
<th>No training</th>
</tr>
</thead>
</table>

Do you identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Do you identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify your ethnic origin or cultural background:

About your views on palliative care

Please rate your degree of confidence with the following patient / family interactions and patient management topics, by ticking the relevant box below

<table>
<thead>
<tr>
<th>1 = Need further basic instruction</th>
<th>2 = Confident to perform with close supervision / coaching</th>
<th>3 = Confident to perform with minimal consultation</th>
<th>4 = Confident to perform independently</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Patient/family interactions and clinical management</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>Answering patients questions about the dying process</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Supporting the patient or family member when they become upset</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Informing people of the support services available</td>
<td></td>
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</tr>
<tr>
<td>4</td>
<td>Discussing different environmental options (eg hospital, home, family)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Discussing patients wishes for after their death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Answering queries about the effects of certain medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Reacting to reports of pain from the patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Reacting to and coping with terminal delirium</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Reacting to and coping with terminal dyspnoea (breathlessness)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Reacting to and coping with nausea / vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Reacting to and coping with reports of constipation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Reacting to and coping with limited patient decision-making capacity</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please continue over the page
Views about death and dying

Please indicate how much you agree or disagree with each of the following statements, by ticking the box that best describes how you feel. (There are no right or wrong answers).

<table>
<thead>
<tr>
<th>No</th>
<th>Statement</th>
<th>Agree Strongly</th>
<th>Agree</th>
<th>Unsure / Mixed</th>
<th>Disagree</th>
<th>Disagree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The end of life is a time of great suffering.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Little can be done to help someone achieve a sense of peace at the end of life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>The use of strong pain medication can cause the person to stop breathing.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I am not comfortable caring for a dying patient.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I am not comfortable talking to families about death.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>When a patient dies I feel that something went wrong.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Feeding tubes should be used to prevent starvation at the end of life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Nursing homes/hospitals are not good places to die.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Families have the right to refuse a medical treatment, even if that treatment prolongs life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Dying patients should be referred to a hospice or acute care.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Attitudes towards Palliative Care

<table>
<thead>
<tr>
<th>No</th>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Disagree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pain at the end of life is an inevitable part of the dying process</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Pain medication should be given as needed to terminally ill patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Spiritual care should include counselling the terminally ill patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I do not like talking about death and dying with patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Patients should have the right to determine their own degree of medical intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Opening discussions of end-of-life care should be deferred until there is no further effective curative treatment available</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Estimation of pain by an MD or RN is a more valid measure of pain than patient self-report</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition such as cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Patients have the right to determine their own degree of psychosocial intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>The most appropriate person to make end-of-life decisions is the patient’s primary care provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>A patient should experience discomfort prior to receiving the next dose of pain medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Patients should be maintained in a pain-free state</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>As a rule, terminally ill patients prefer not to talk about death and dying</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please indicate the importance of the issues below in terms of the problems they create for you in caring for a dying patient by ticking the box that best describes your feelings. (There are no right or wrong answers).

<table>
<thead>
<tr>
<th>No</th>
<th>Statement</th>
<th>Very important</th>
<th>Important</th>
<th>Unsure</th>
<th>Less important</th>
<th>Not important</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Control of pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Managing depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Legal concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Ability to meet spiritual needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>The patient’s emotional needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Communication with family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Communication with other palliative care staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Communication with (other) doctor/s</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Uncertainty about what is best care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Other (please describe)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please tick the boxes to indicate whether you would like future education on any of the following topics:

<table>
<thead>
<tr>
<th>Topic</th>
<th>Education needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain assessment and management</td>
<td>Dealing with terminal delirium</td>
</tr>
<tr>
<td>Dealing with nausea and vomiting</td>
<td>Dealing with terminal dyspnea</td>
</tr>
<tr>
<td>Dealing with constipation</td>
<td>Use of intravenous hydration and/or non-orai feeding in end-of-life care</td>
</tr>
<tr>
<td>End-of-life communication skills - giving bad news, talking with family, discussing prognosis, discussing various treatment options</td>
<td>End-of-life ethics: DNR orders, advance directives, decision-making capacity</td>
</tr>
<tr>
<td>Spirituality and cultural aspects of end-of-life care</td>
<td>Other (please specify below)</td>
</tr>
</tbody>
</table>

Please list any other topics here

This is the end of the survey. Thank you for your time.

Reference:

Appendix 7.

LIVERPOOL BASE

END-OF-LIFE AUDIT TOOL
LIVERPOOL END-OF-LIFE CARE PATHWAY: BASE REVIEW

Centre Name:

Centre Type:  Patient Identifier:  Pat Age:
- Hospital  -  -  -  -  -  -  -
- Hospice
- Community
- Nursing Home

Gender (Please circle):  Admit Date:  Death Date:
- M  -  -
- F  -  -

Primary Diagnosis – please refer to data dictionary (please tick only one)

Cancers:
- Bone (sarcoma)
- Breast
- Eye
- Meninges
- Brain
- Anus
- Colon
- Oesophagus
- Rectum
- Small Intestine
- Stomach
- Adrenal
- Carcinoid
- Neuroendocrine
- Thyroid
- ENT
- Female Genital Organs
- Leukaemia
- Lymphoma
- MDS
- Myeloma

- Gall Bladder
- Liver
- Pancreas
- Penis
- Prostate
- Testis
- Mesothelioma
- Other Connective/soft tissue disorders
- Bronchus
- Non Small Cell Lung
- Small Cell Lung
- Trachea
- Malignant Melanoma
- Non Melanoma
- Bladder
- Kidney
- Ureter
- Cancer - Primary Multiple sites
- Unknown Primary
- Other Cancer

Non Cancers:
- Acute abdomen
- Arthritis
- MI, CCF
- Stroke
- Alzheimers
- Epilepsy
- Motor Neurone Disease
- MS
- Parkinsons Disease
- CNS Other
- Hepatobiliary
- HIV/AIDS
- Renal
- Respiratory
- Vascular
- Other Non Cancer

For “Patient identifier” please enter a number which uniquely identifies your patient. Please enter it on each page in proforma.
LIVERPOOL END-OF-LIFE CARE PATHWAY: BASE REVIEW

COMFORT MEASURES

1.1 Pain current medication assessed and non essentials discontinued □ Yes □ No

1.2 If other medication not discontinued was a documented reason given □ Yes □ No

2. Was as required (PRN) □ Yes □ No

2.1 Analgesic □ Yes □ No

2.2 Antiemetic □ Yes □ No

Prescribed subsequently: □ Yes □ No

2.3 Anticholinergic □ Yes □ No

2.4 Sedative □ Yes □ No

2.5 If yes were drugs prescribed the ones recommended in your local formulary guidelines □ Yes □ No

3. Were the following interventions discontinued:

3.1 Blood Tests □ Yes □ No □ Not Applicable

3.2 Antibiotics □ Yes □ No □ Not Applicable

3.3 Intravenous Fluids □ Yes □ No □ Not Applicable

3.4 Were do not resuscitate instructions documented □ Yes □ No □ Not Applicable

3.5 Were instructions re do not transfer to hospital documented □ Yes □ No □ Not Applicable

3a Were inappropriate nursing interventions discontinued:

3a1 Routine Turning Regime □ Yes □ No □ Not Applicable

3a2 Taking vital signs □ Yes □ No □ Not Applicable

3b Was a syringe driver set up within 4 hours of prescription □ Yes □ No □ Not Applicable

PSYCHOLOGICAL / INSIGHT ISSUES

4. Ability to communicate in English Assessed □ Yes □ No □ Not Applicable

5.1 Patient aware of diagnosis? □ Yes □ No

5.2 If no is there a documented reason □ Yes □ No □ Not Applicable

5.3 Patient aware s/he is dying? □ Yes □ No

5.4 Next of kin aware patient is dying? □ Yes □ No

RELIGIOUS NEEDS

6.1 Patients religious needs assessed □ Yes □ No □ Not Applicable

6.2 Patients religious needs met □ Yes □ No □ Not Applicable

COMMUNICATION WITH FAMILY – OTHERS – PRIMARY HEALTH CARE TEAM

7. Identified how family/others were to be contacted/Informed of patients impending death? □ Yes □ No □ Not Applicable

8. Family/others given written information re facilities □ Yes □ No □ Not Applicable

9. Patients GP/Locum service aware that patient in dying Phase □ Yes □ No □ Not Applicable

10. Patients plan of care discussed with family/others □ Yes □ No □ Not Applicable
LIVERPOOL END-OF-LIFE CARE PATHWAY: BASE REVIEW

SECTION 2: ONGOING ASSESSMENTS

S2.1  Assessment of pain 4 hourly/each visit □ Yes □ No
S2.2  Was the patient in pain □ Yes □ No
S2.3  Was pm analgesia given □ Yes □ No
S2.4  Assessment of nausea & vomiting 4 hourly/each visit □ Yes □ No
S2.5  Was nausea & vomiting a problem □ Yes □ No
S2.6  Was pm antiemetic given □ Yes □ No
S2.7  Assessment of agitation 4 hourly/each visit □ Yes □ No
S2.8  Was agitation a problem □ Yes □ No
S2.9  Was pm sedation given □ Yes □ No
S2.10 Assessment of excessive respiratory secretion 4 hourly/each visit □ Yes □ No
S2.11 Was excessive respiratory secretions a problem □ Yes □ No
S2.12 Was pm anticholinergic given □ Yes □ No
S2.13 Assessment of mouth care 4 hourly/each visit □ Yes □ No
S2.14 Assessment of Micurion problems 4 hourly/each visit □ Yes □ No
S2.15 If pressure relieving aids required were these provided □ Yes □ No
S2.16 Assessment of Bowel Care 12 hourly/each visit □ Yes □ No

CARE AFTER DEATH

S3.1  GP/Locum Service contacted re patients death □ Yes □ No
S3.2  Post Mortem discussed □ Yes □ No □ Not Applicable
S3.3  Special Needs identified / religions / infection needs □ Yes □ No
S3.4  Family/others informed of tasks following death □ Yes □ No
S3.5  Appropriate documentation given to family/others □ Yes □ No

Reference:

Appendix 8.

**Chart Audit Letter:**

**Residential Aged Care**
Rural Palliative Care Project: R-PAC Project

[Insert date]

[Insert RACF Address]

Dear [Insert DON name]

R-PAC Project: focussed chart audits

Many thanks for agreeing to participate in the focus chart audit to be conducted on the nursing notes of residents who have died in your facility. The protocol for the chart audit is attached.

Prof Patricia Davidson, University of Western Sydney and I propose to undertake this audit in your facility on the [insert date], please let me know if this is not suitable and we can arrange to complete these chart audits at a more convenient time. In order to undertake the chart audit, we will need access to all of the deceased resident’s notes from:

- 1st September – 31st December [Insert year]

If you have any questions or would like to discuss this further, please don’t hesitate to contact me on 041 1100 617.

Yours sincerely

Jane Phillips
Rural Palliative Care Program Coordinator
Protocol: Focussed end-of-life care chart audit

Background: Internationally the number of people dying in residential aged care facilities is growing; prompting an analysis of end-of-life care. The use of a focus chart audit has been advocated as one method by which to measure the quality of care provided to dying residents. Previous studies have utilised the information obtained from a focus chart audit to identify and address gaps in care provision, develop educational strategies for health care providers and establish best practice care protocols (1-2).

Aim: To undertake a quality activity to assess the level of care provided to dying residents and to assess the impact that a targeted intervention has on the provision of end-of-life care to residents who died within local residential aged care facilities.

Objectives: To complete a focus chart audit of the care provided in the last 72 hours for all residents who died in local residential aged care facilities at two points in time.

Design: A retrospective chart audit utilising a modified Liverpool end-of-life audit tool (7) focusing on the last 72 hours of life of all residents who died during September through to December 2003 (pre-test) and September through to December 2005 (post-test) in local residential aged care facilities will be used to assess the quality and level of palliative care provided.

Because this quality activity will only involve chart review, with no identifying resident information being collected or included in the audit data or reported, it is not proposed that consent will be sought from the deceased resident’s families (9).

Ethical approval has been granted from the University of Western Sydney to undertake this audit: HREC 05/096.

Setting: That permission be sought from all participating local residential age care facilities (N=9) in Coffs Harbour local government area to participate in the focus chart audit.

Sample: These nine local residential aged care facilities provide care to 598 older people. During 2003, a total of 189 residents died, with 79% of these deaths being managed within the facility.

Based on this data it is estimated that this chart audit will consist of approximately 80 deceased residents’ notes.

This audit will be conducted on the nursing notes of all residents who died in a participating residential aged care facility during a three month period from the:

- 1st September, 2003 through to the 31st December 2003 (pre-test)
- 1st September, 2005 through to the 31st December 2005 (post-test)

Those who died suddenly from a sudden cardiac event or other acute episode or died in hospital will be excluded.
Rural Palliative Care Project: R-PAC Project

Protocol: Focussed end-of-life care chart audit

**Measurements:** A modified Liverpool end-of-life audit tool will be used \(^{(1)}\). The only identifying data that will be collected will be the resident's date of birth and their unique facility medical record number.

**Reporting:** The data obtained from this audit will be presented in a de-identified manner. A quality report will be produced for each participating residential aged care facility. The data will be used as part of my PhD study. It is my intention to publish the findings of the audit in a peer reviewed journal.

If you have any questions or would like to discuss this chart audit protocol further, please don't hesitate to contact me on 041 1100 817.

Yours sincerely

Jane Phillips
Ms Jane Phillips
Rural Palliative Care Program Coordinator

**REFERENCE LIST**


Appendix 9.

Expressions of Interest Letter:

Residential Aged Care – Link Nurses
Rural Palliative Care Project

[Insert date]

[Insert RACF Address]

Expressions of Interest

Palliative Care Link Nurses

The Mid North Coast Rural Palliative Care Project is calling for expressions of interest from Registered Nurses who are interested in becoming Palliative Care Link Nurses within their aged care facility.

As a Palliative Care Link Nurse you are given an opportunity to develop your palliative care knowledge and skills by:

- Participating in a 2 Day Palliative Care Workshop to be held in Coffs Harbour on Thursday 7th October, 2004 and Friday 8th October, 2004, facilitate by RSL Care & Dr Debra Prior, Australian Catholic University.
- Undertaking a 2 day field placement during the next 12 months with the Palliative Care Team based at Coffs Harbour Health Campus; and
- Participate in another 1 day palliative care in-service in 2005.

You will also be provided with an opportunity to attend a bi-monthly Palliative Care Link Nurse Network Meeting. These meetings will provide you with an opportunity to share your information and experiences and provide you with additional palliative care educational opportunities. All of this is about developing your palliative care competencies. For an additional fee, you will also be eligible to enrol in and complete the distance education module “palliative care and the older person” and on completion of this module have 10 credit points towards a graduate diploma in palliative care nursing.

In return for this palliative care educational opportunity, you will be required to act as a palliative care resource person in your aged care facility, contribute to the management of residents requiring palliative care and conduct a minimum of two education sessions per year for your peers at your place of work.

So if you think you have what it takes to enhance local palliative care within your establishment, then the Project Team would love to hear from you. We are looking for registered nurses with the following qualities:
Appendix 9

Essential criteria
- Registered Nurse – current registration
- Currently employed for more than 16 hours per week
- Demonstrated interest in palliative care

Desirable criteria
- Post registration qualifications: palliative care, aged care and/or education
- Basic computer skills – (MS Word, Outlook and Internet Explorer)
- Professional commitment to improving the provision of palliative care
- Demonstrated ability to be an active team member.

Please send you CV and Application, addressing the following criteria to: Ms Jane Phillips, MNC Rural Palliative Care Project Co-ordinator, MNC/GP, PO Box 920, Coffs Harbour NSW 2450 by the close of business, Friday 20th August, 2004.

If you would like more information please phone Jane Phillips on (02) 6659 3652. Information about the project is attached.

Yours sincerely

Jane A. Phillips
Ms. Jane Phillips
Rural Palliative Care Program Coordinator
Appendix 10.

PALLIATIVE APPROACH WORKSHOP:

LINK NURSES
### Thursday 7 October 2004 (0830 –1830)

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0830</td>
<td><em>Registration/ Coffee/Tea</em></td>
</tr>
<tr>
<td>0900</td>
<td>1. Welcome – Setting the scene</td>
</tr>
<tr>
<td>0930</td>
<td>2. Introductions &amp; reflecting on expectations</td>
</tr>
<tr>
<td>1000</td>
<td>3. Philosophy and meaning of a palliative approach</td>
</tr>
<tr>
<td>1030</td>
<td><em>Morning Tea</em></td>
</tr>
<tr>
<td>1045</td>
<td>4. Ethical and legal issues</td>
</tr>
<tr>
<td>1230</td>
<td><em>Lunch</em></td>
</tr>
<tr>
<td>1315</td>
<td>5. Principles of holistic assessment</td>
</tr>
<tr>
<td>1400</td>
<td>6. Interactive symptom management workshop</td>
</tr>
<tr>
<td></td>
<td>Part 1: Assessment and management of dyspnoea, restlessness and delirium</td>
</tr>
<tr>
<td>1500</td>
<td><em>Afternoon Tea</em></td>
</tr>
<tr>
<td>1515</td>
<td>7. Part 2: Symptom management: Assessment and management of nausea and</td>
</tr>
<tr>
<td></td>
<td>vomiting, nutrition and hydration, constipation</td>
</tr>
<tr>
<td>1600</td>
<td>8. Summary: Reflections. Questions and feedback</td>
</tr>
<tr>
<td></td>
<td>Case study introduction</td>
</tr>
<tr>
<td>1630</td>
<td>9. Close</td>
</tr>
<tr>
<td>1700</td>
<td><em>Networking and drinks – Oh, La La Café 1st Avenue, Sawtell</em></td>
</tr>
</tbody>
</table>

### Friday 8 October 2004 (0800 –1630)

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0800</td>
<td><em>Registration/ Coffee/Tea</em></td>
</tr>
<tr>
<td>0830</td>
<td>1. Interactive symptom management workshop</td>
</tr>
<tr>
<td></td>
<td>Part 3. Assessment and management of pain</td>
</tr>
<tr>
<td>10.30</td>
<td><em>Morning Tea</em></td>
</tr>
<tr>
<td>1015</td>
<td>2. Overview of the pharmacology of palliative care medications</td>
</tr>
<tr>
<td>1015</td>
<td>3. Panel discussion – analysis of a resident’s story</td>
</tr>
<tr>
<td>1230</td>
<td><em>Lunch</em></td>
</tr>
<tr>
<td>1315</td>
<td>4. Living, dying and death: recognising and managing end-of-life care;</td>
</tr>
<tr>
<td></td>
<td>rituals and ceremonies, loss, grief and bereavement</td>
</tr>
<tr>
<td>1500</td>
<td><em>Afternoon Tea</em></td>
</tr>
<tr>
<td>1515</td>
<td>5. Communicating with residents and families: providing effective psycho-</td>
</tr>
<tr>
<td></td>
<td>social support</td>
</tr>
<tr>
<td>1600</td>
<td>6. Reflections, next steps – making it happen and evaluation</td>
</tr>
<tr>
<td>1630</td>
<td>7. Close</td>
</tr>
</tbody>
</table>
Appendix 11.

Adult Education Workshop:

Link Nurses
# RESIDENTIAL AGED CARE

**LINK NURSE – ADULT EDUCATION STRATEGIES WORKSHOP**

**Coffs Harbour Health Campus**

**Education Centre**

**Friday 1 September 2006 (0830 – 1700)**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>0830</td>
<td>Registration/ Coffee/Tea</td>
</tr>
<tr>
<td>0900</td>
<td>1. Welcome – Setting the scene</td>
</tr>
<tr>
<td>0930</td>
<td>2. Introductions, ice breaker &amp; reflecting on expectations</td>
</tr>
<tr>
<td>1000</td>
<td>3. Principles of adult learning, learning styles &amp; barriers</td>
</tr>
<tr>
<td>1030</td>
<td><strong>Morning Tea</strong></td>
</tr>
<tr>
<td>1045</td>
<td>4. Communication exercise – break into five groups</td>
</tr>
<tr>
<td>1100</td>
<td>5. Introduce session plan &amp; decide on focus of aspect of syringe driver in-service</td>
</tr>
<tr>
<td>1130</td>
<td>6. Session planning – introduce <strong>GLOSS</strong> – Explore strategies to:</td>
</tr>
<tr>
<td></td>
<td>• Grab attention;</td>
</tr>
<tr>
<td></td>
<td>• Link to other sessions;</td>
</tr>
<tr>
<td></td>
<td>• Outcomes intended;</td>
</tr>
<tr>
<td></td>
<td>• Structure – what will happen;</td>
</tr>
<tr>
<td></td>
<td>• Stimulus – purpose, what does it mean what will I get out of it);</td>
</tr>
<tr>
<td>1220</td>
<td>7. Focusing on the Body – where most of the work happens: content,</td>
</tr>
<tr>
<td></td>
<td>requirements &amp; desired outcomes &amp; practice</td>
</tr>
<tr>
<td>1300</td>
<td>8. Conclusion session planning: introduce <strong>O.F.F</strong></td>
</tr>
<tr>
<td></td>
<td>• Outcome – revisit;</td>
</tr>
<tr>
<td></td>
<td>• Feedback – self assessment; and</td>
</tr>
<tr>
<td></td>
<td>• Future – next session</td>
</tr>
<tr>
<td>1330</td>
<td><strong>Lunch</strong></td>
</tr>
<tr>
<td>1415</td>
<td>9. 15 minute syringe driver in-service presentations by 5 groups</td>
</tr>
<tr>
<td>1530</td>
<td>10. Feedback session</td>
</tr>
<tr>
<td>1500</td>
<td><strong>Afternoon Tea</strong></td>
</tr>
<tr>
<td>1600</td>
<td>11. Discuss timetable for assessment &amp; requirements</td>
</tr>
<tr>
<td>1630</td>
<td>12. Reflections, next steps – making it happen and evaluation</td>
</tr>
<tr>
<td>1700</td>
<td>13. Close</td>
</tr>
</tbody>
</table>
Appendix 12.

PALLIATIVE APPROACH COURSE:

CARE ASSISTANTS & ENROLLED NURSES
# PALLIATIVE APPROACH WORKSHOP
## CARE ASSISTANTS & ENROLLED NURSES
Mater Christi Retirement Village
Sawtell

## WEEK 1 (0830 –1300): Setting the scene: why a palliative approach

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0830</td>
<td><strong>Registration/ Coffee/Tea</strong></td>
</tr>
<tr>
<td>0900</td>
<td>1. Welcome – Setting the scene</td>
</tr>
<tr>
<td>0910</td>
<td>2. Introductions &amp; reflecting on expectations</td>
</tr>
<tr>
<td>0930</td>
<td>3. Exploring what we mean by a “good death” – small groups</td>
</tr>
<tr>
<td>1030</td>
<td><strong>Morning Tea</strong></td>
</tr>
<tr>
<td>1045</td>
<td>4. Introduction to a palliative approach</td>
</tr>
<tr>
<td>1110</td>
<td>5. Palliative approach case discussion – identifying when a palliative</td>
</tr>
<tr>
<td></td>
<td>approach; specialist palliative care and end–of–life care was indicated</td>
</tr>
<tr>
<td></td>
<td>– small group work</td>
</tr>
<tr>
<td>1130</td>
<td>6. Feedback from the groups</td>
</tr>
<tr>
<td>1200</td>
<td>7. Professional responsibility &amp; a palliative approach</td>
</tr>
<tr>
<td>1250</td>
<td>8. Summary: Reflections. Questions and feedback</td>
</tr>
<tr>
<td></td>
<td>Preparation activities for next week</td>
</tr>
<tr>
<td>1300</td>
<td>9. Close</td>
</tr>
</tbody>
</table>

## WEEK 2 (0830 –1300): Assessment and management of symptoms and end–of–life care

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0800</td>
<td><strong>Networking – Coffee/Tea</strong></td>
</tr>
<tr>
<td>0830</td>
<td>1. Welcome back. Recapping and reflecting on last week &amp; discussion on feed</td>
</tr>
<tr>
<td></td>
<td>back activities</td>
</tr>
<tr>
<td></td>
<td>• Locating the palliative approach guidelines</td>
</tr>
<tr>
<td></td>
<td>• Identifying and making contact with the Link Nurses</td>
</tr>
<tr>
<td>0900</td>
<td>2. Death and dying: indicators of dying</td>
</tr>
<tr>
<td>0930</td>
<td>3. End–of–life care planning, decision making and advance care planning</td>
</tr>
<tr>
<td>1000</td>
<td>4. Exploring the myths about pain in older people – sentence stems – group</td>
</tr>
<tr>
<td></td>
<td>work</td>
</tr>
<tr>
<td>1030</td>
<td><strong>Morning Tea</strong></td>
</tr>
<tr>
<td>1045</td>
<td>5. Pain assessment – small group work</td>
</tr>
<tr>
<td>1100</td>
<td>6. Reporting back and group discussion</td>
</tr>
<tr>
<td>1130</td>
<td>7. Symptom assessment and management – three case studies – small group</td>
</tr>
<tr>
<td></td>
<td>work</td>
</tr>
<tr>
<td>1250</td>
<td>8. Summary: Reflections. Questions and feedback</td>
</tr>
<tr>
<td></td>
<td>Preparation activities for next week</td>
</tr>
<tr>
<td>1300</td>
<td>9. Close</td>
</tr>
</tbody>
</table>
# PALLIATIVE APPROACH WORKSHOP
**CARE ASSISTANTS & ENROLLED NURSES**
Mater Christi Retirement Village
Sawtell

## WEEK 3: (0830 –1300): Providing psychological, cultural and spiritual support

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0800</td>
<td>Networking/ Coffee/Tea</td>
</tr>
</tbody>
</table>
| 0830  | 1. Welcome back. Recapping and reflecting on last week & discussion on feed back activities  
  * Feedback about use of the pain assessment tools(s) |
| 0900  | 2. Psychological: managing anxiety, confusion and depression in the older person. Small group work. Feedback and discussion |
| 0930  | 3. Social: Time/life line. Consider support systems and sexuality 20–40 years; 40–60 years and 60 plus – large group |
| 0950  | 4. Cultural: Exploring what defines us culturally: large group discussion and how our cultural beliefs may impact on: pain; loss and grief; and family support – small groups: |
| 1010  | 5. Spiritual: Exploring strategies to assist the resident to express their spiritual needs. Small group work. Feedback & discussion |
| 1030  | Morning Tea                                                              |
| 1045  | 6. Impact of loss and grief –case study. Small group work. Feed back and discussion |
| 1200  | 6. Care of self and others: small group work (rituals and ceremonies, individual coping and organisational support), feed back and discussion. |
| 1250  | 7. Summary: Reflections. Questions and feedback  
  Preparation activities for next week |
| 1300  | 8. Close                                                                  |

## WEEK 4: (0830 –1300) Making a palliative approach happen

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0800</td>
<td>Networking/ Coffee/Tea</td>
</tr>
</tbody>
</table>
| 0830  | 1. Welcome back. Recapping and reflecting on last week & discussion on feed back activities  
  * Care of self and others |
| 0900  | 2. Review of the learning goals set in week 1 – exploring the themes – filling the gaps |
| 1030  | Morning Tea & certificate presentation                                    |
| 1045  | 3. Dementia as a life limiting illness                                   |
| 1130  | 4. Making a palliative approach happen in your aged care facility: small group work with Link Nurses  
  Feed back and discussion |
| 1245  | 5. Reflections, next steps, maintaining contact and evaluation           |
| 1300  | 6. Close                                                                  |
Appendix 13.

PALLIATIVE APPROACH WORKSHOP:

REGISTERED NURSES
## RESIDENTIAL AGED CARE
### REGISTERED NURSE WORKSHOP
**Mater Christi Retirement Village**
**Sawtell**

**Thursday 11 August 2005 (0830 -1700)**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0830</td>
<td>Registration/ Coffee/Tea</td>
</tr>
<tr>
<td>0900</td>
<td>1. Welcome – Setting the scene</td>
</tr>
<tr>
<td>0910</td>
<td>2. Introductions &amp; reflecting on expectations</td>
</tr>
<tr>
<td>0930</td>
<td>3. Exploring what we mean by a &quot;good death&quot;</td>
</tr>
<tr>
<td>1000</td>
<td>4. Communication challenges – role play</td>
</tr>
<tr>
<td>1115</td>
<td>5. Communication role plays – small groups</td>
</tr>
<tr>
<td>1230</td>
<td>Lunch</td>
</tr>
<tr>
<td>1315</td>
<td>6. Managing Ethical issues – small groups–</td>
</tr>
<tr>
<td>1400</td>
<td>7. Advance care planning</td>
</tr>
<tr>
<td>1445</td>
<td>Afternoon Tea</td>
</tr>
<tr>
<td>1500</td>
<td>8. Managing end–of–life care; rituals and ceremonies, loss, grief and bereavement</td>
</tr>
<tr>
<td>1600</td>
<td>9. Assessment of pain – introduction to appropriate tools</td>
</tr>
<tr>
<td>1600</td>
<td>10. Summary: Reflections. Questions and feedback Case study introduction</td>
</tr>
<tr>
<td>1700</td>
<td>11. Close</td>
</tr>
</tbody>
</table>

**Friday 12 August 2005 (0800–1700)**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0800</td>
<td>Networking – Coffee/Tea</td>
</tr>
<tr>
<td>0830</td>
<td>1. Recapping and reflecting</td>
</tr>
<tr>
<td>0930</td>
<td>2. Interactive sessions: pain and older people – exploring the myths</td>
</tr>
<tr>
<td>1015</td>
<td>Morning Tea</td>
</tr>
<tr>
<td>1015</td>
<td>3. Overview of the pharmacology of palliative care medications – drug issues and calculations</td>
</tr>
<tr>
<td>1200</td>
<td>Lunch</td>
</tr>
<tr>
<td>1315</td>
<td>5. Symptom management – three case studies</td>
</tr>
<tr>
<td>1400</td>
<td>6. Dementia as a life limiting illness</td>
</tr>
<tr>
<td>1445</td>
<td>Afternoon Tea</td>
</tr>
<tr>
<td>1500</td>
<td>7. Communicating with residents and families: providing effective psycho–social and spiritual support</td>
</tr>
<tr>
<td>1645</td>
<td>8. Reflections, next steps and evaluation</td>
</tr>
<tr>
<td>1700</td>
<td>9. Close</td>
</tr>
</tbody>
</table>
Appendix 14.

_PALLIATIVE APPROACH PAMPHLET_
A palliative approach is another stage of caring...

Betty had recently admitted her husband John, who has Parkinson’s disease and advanced dementia to residential aged care. Betty has managed all of John’s care at home, with support from their general practitioner, the community nurses and regular visits to the neurologist (medical specialist).

Over the past 12 months it had become progressively harder for Betty to manage John’s care, as he was no longer able to walk well, had difficulty getting into the car and was getting more agitated, combative and distressed, particularly in unfamiliar surroundings.

Betty was anxious that John’s care be maintained but was unsure how John would cope if going to see his medical specialist. Shortly after admission the aged care staff, John’s GP and Betty all met to discuss John’s care needs. At this meeting it was decided that the focus of care be on maintaining John’s comfort and dignity. Given the distress that John experienced in different environments it was decided that the GP would manage John’s Parkinson’s symptoms and would seek expert advice from John’s neurologist as required.

Betty was comfortable with this decision and described a palliative approach as “another stage of caring”.

For further information or support:
- NSW Guardianship Tribunal
  1800 463 928
  www.gtt.nsw.gov.au
- Public Trustee NSW
  02 9262 6525
  www.ptt.nsw.gov.au
- Office of the Public Guardian
  1800 451 510
  www.lawlink.nsw.gov.au
- Palliative Care NSW
  02 9262 6456
  www.palliativecare.nsw.org.au
- Alzheimer’s Australia Helpline
  1800 106 500
  www.alzheimers.org.au
- Commonwealth Carelink Centre
  1800 052 222
  www.carelink.health.gov.au

Acknowledgments:
- Department of Health and Ageing – National Palliative Care Program
  - Spinal Injuries Information and Referral Line: 1800 667 720
  - National Palliative Care Foundation: 1800 667 720
A Palliative Approach

Our residential aged care facility is committed to delivering a palliative approach. Adopting this approach enables care to be focused on improving each resident’s quality of life and maintaining their dignity and comfort. This includes the early identification, assessment and treatment of pain and the effective management of other symptoms such as restlessness, agitation, confusion, nausea and shortness of breath. It also ensures that each resident’s psychological, social and spiritual needs are met. A palliative approach also helps us to acknowledge the needs of the person and their family and engage the relevant health care providers (doctors, nurses and allied health staff) in planning and delivering care. At times a palliative approach may include active treatment for a progressive life-limiting illness even though a cure is not possible. It is careful that can be initiated well before the terminal stages of illness.

The nurses and care assistants in our facility have the necessary education and training to deliver a palliative approach. We have a supportive relationship with the specialist palliative care and aged care teams. At times, we may ask these specialists to provide input into our resident’s care. It may also be comforting to know that if required, we are able to provide the best possible end-of-life care within the facility.

Decision Making

Keeping you informed of any changes in treatment and care is an important element of a palliative approach. At some stage you may be asked to make some decisions about the level and type of care provided. These decisions can sometimes be quite difficult to make as they may relate to determining:

- Under what circumstances is it safe to consider a hospital for treatment to be considered?
- What type and level of medical treatment or care should be considered for the management of a major or recurrent infection, heart attack or a stroke?
- How should we manage the consequences of a fall or problems associated with difficulty swallowing food?

As these are often complex decisions, it can be helpful to start thinking about these questions and to discuss them with those closest to you. Discussing these issues with others helps ensure that they are aware of how you think your care should be managed in certain circumstances and at the end of life.

Advance Care Planning

Advance care planning is a process which offers you or your family member the opportunity to discuss the choices for care at the end of life. The discussions usually involve the family, the general practitioners and the aged care team. Having these discussions provides an opportunity to explore the important issues concerning the questions, fears and values you may have. As the issues are uncovered, the information can be written into a plan of action called an Advance Care Plan. Having an Advance Care Plan in place will help to ensure that all members of the care team are aware of your wishes regarding future medical treatment, particularly treatment at the end of life.

As part of your Advance Care Planning, you may wish to complete an Advance Health Care Directive. This is a written document in which you state your wishes or directions regarding your health care if at some time in the future you cannot speak for yourself. A staff member in the facility or your General Practitioner may assist you to obtain and complete an Advance Health Care Directive.

Enduring Guardian

In addition to discussing your wishes with your family and health care providers, you may wish to appoint an Enduring Guardian. An Enduring Guardian is a person over 18 years of age who you appoint to make decisions on your behalf about your health care and other personal matters if you are no longer able to do so. The person needs to agree to the appointment, and they should be prepared to carry out your wishes as far as is possible. Most people appoint a close family member or friend as their Enduring Guardian, and a staff member in the facility will be able to obtain an Appointment of Enduring Guardian form for you.