

Comprehensive Evidence-Based Palliative Approach in Residential Aged Care

Final Report

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**Encouraging Best Practice in
Residential Aged Care Program**

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Abbreviations

ACFI	Aged Care Funding Instrument
AHD	Advance Health Directive
APS	Australian Pain Society
APRAC	Australian Palliative Residential Aged Care Project
BSPCC	Brisbane South Palliative Care Collaborative
CALD	Culturally and Linguistically Diverse
CAM	Confusion Assessment Method
CEBPARAC	Comprehensive Evidence-Based Palliative Approach in Residential Aged Care
CNC	Clinical Nurse Consultant
CNS	Clinical Nurse Specialist
CW	Careworker or Assistant-in-nursing
DoHA	Department of Health and Ageing
EBPRAC	Encouraging Best Practice in Residential Aged Care
EEN	Endorsed Enrolled Nurse
EN	Enrolled Nurse
EPOA	Enduring Power of Attorney
EoLCP	End of Life Care Pathway
GP	General Practitioner
IQR	Interquartile Range
LN	Link Nurse
NICS	National Institute for Clinical Studies
NHMRC	National Health and Medical Research Council
n.s.	not significant
PL	Project Liaison
PM	Project Manager
prn	As required
RAC EoLCP	Residential Aged Care End of Life Care Pathway
RACF	Residential aged care facility
RACGP	Royal Australian College of General Practitioners
RACPAN	Residential Aged Care Palliative Approach Network
RN	Registered Nurse
RNAO	Royal Nurses Association of Ontario
RPDC	University of Queensland/Blue Care Research & Practice Development Centre

Part B – Main messages (maximum 1 page)

1. Implementing evidence based guidelines in residential aged care requires a comprehensive approach with includes education of all staff and the support of management.
2. An evidence based palliative approach to resident care improves resident and family outcomes.
3. A comprehensive palliative approach education program improves staff confidence to provide a palliative approach for residents and families.
4. A systematic approach to advance care planning provides opportunity for residents wishes regarding care decisions including place of care to be respected.
5. A palliative care case conference facilitates the identification of resident and family palliative care needs and provides a structure for multidisciplinary care planning.
6. A palliative care case conference means that all health professionals, the resident and family are “on the same page” with regard to palliative care wishes and needs.
7. The use of an end of life care pathway such as the RAC EoLCP improves the terminal care provided to residents and their families.
8. Training is required for staff to convene palliative care case conferences and the use end of life care pathways.
9. Separate educational resources (with consistent messages) are required for staff with differing skills.

Part C – Executive summary (maximum of 3 pages)

Aims and Objectives

The aim of this project was to implement and evaluate a comprehensive evidence based palliative approach in residential aged care.

The objectives of the project were to:

1. Translate existing evidence based guidelines (palliative care and pain management) into policy and practice (including documentation).
2. Provide education to all nursing and care staff at all levels working in the RACFs using existing training materials.
3. Establish, train and support link nurses in each RACF.
4. Promote the use of existing GP on-line training modules to support GPs in providing a palliative approach to residents in their care.
5. Implement the BSPCC Residential Aged Care End-of-life Care Pathway (RAC EoLCP) for residents requiring terminal care.
6. Develop a palliative care case conferencing learning resource (DVD and hard copy) for residents and family members, nursing staff and GPs.
7. Develop from existing training modules a self-directed learning module for Link nurses.

Evidence implementation

The evidence utilised in this study included:

- Guidelines for a Palliative Approach in Residential Aged Care – Enhanced Version – May 2006
- Pain in Residential Aged Care Facilities: Management Strategies – August 2005

The evidence implementation model was based on National Institute for Clinical Studies (NICS) recommendations of implementing evidence into clinical practice. In short this included understanding the local context, translation of guidelines into a model of care based on six key domains of clinical practice and identification of resources required for implementation. Where, in this instance not all resources were available these were developed (Full details are in section 2).

The context of implementation

The model of care was implemented in nine RACFs, across four states (New South Wales, Queensland, South Australia and Western Australia). These facilities represented not-for-profit (Blue Care), private (Padman Health Services, Boandik Lodge, and Brightwater) and government-operated (Queensland Health) organisations. Facilities were based in metropolitan (n=5), outer metropolitan (n=2), and regional areas (n=2). Number of beds per facility ranged from 48 to 130 beds. All facilities catered for high care residents with two facilities also caring for low care residents. No facilities reported a significant level of cultural diversity in their residents.

Resources developed to assist with implementation

Although the palliative approach and pain guidelines existed, they were not in a format that was easily translated for implementation. Consequently, the CEBPARAC project developed a Toolkit, featuring six key domains of care and accompanying education resources (Full details are in section 3.1.2). Resource development included a DVD – “All on the same page” which provided information on advance care planning and palliative care case conferences in residential aged care.

Six Domains of Care
 (1) Family care
 (2) Psychological care of the resident
 (3) Physical symptoms
 (4) Dementia
 (5) Advance care planning
 (6) Terminal care

Following implementation and extensive feedback from all key stakeholders the final Toolkit has been revised. The box below details the final products.

Final CEBPARAC resources

The Palliative Approach Toolkit (PA Toolkit) has the following components

Three modules:

- (1) **Integrating a palliative approach for managers** (guidelines, standards, ACFI, quality control, staff education, role of link nurse);
- (2) **Key processes in a palliative approach** (advance care planning, palliative care case conferences, end of life care pathways); and
- (3) **Clinical care** (pain, dyspnoea, nutrition and hydration, mouth care, and delirium. The clinical care modules were organised into a “see, say, do, write and review format”.
 See: Recognition and assessment
 Say: Report assessment
 Do: Manage symptoms
 Write: Document your actions
 Review: Evaluate and re-assess as necessary

Education products:

- (1) 2 DVDs:
 “All on the same page” (Developed by the project)
 “Suiting the needs” (Existing Palliative Care Australia resource)
- (2) Three self-directed learning packages (these packages will utilise case studies from the two DVDs):
 (a) Nurse (RN/EN introduction);
 (b) Nurse (RN/EN advanced); and
 (c) Care staff (Introduction)
- (3) A Calendar of Posters that can be rotated to cue key messages of a palliative approach.
- (4) Five educational flip charts: The presentations are mapped to the clinical care topics and target care staff.

Also included in the PA Toolkit is a copy of:

- (1) Therapeutic Guidelines: Palliative Care version 3 (Existing resource)
- (2) Palliative Care Australia Standards (Existing resource)
- (3) Brochure – Now What? Understand Grief (Existing resource)
- (4) Brochure – Understanding the Dying Process (Existing resource)
- (5) Guidelines for a Palliative Approach in Residential Aged Care – Enhanced Version (Existing resource)

What was achieved?

This project has been successful in implementing a comprehensive evidence based palliative approach in residential aged care. Achievements are numerous and outlined in detail in the Section 3 (Results). Most significant include:

- Demonstrated improvements in the clinical care of residents such as symptom management, communication with families, advance care planning, bereavement care, referrals to specialist services (palliative care, pain management) and care in the final days of life.
- Demonstrated improvement in knowledge and skills of staff in providing a palliative approach. This has been achieved using the educational resources developed for the project as well as existing resources that had not been accessed. In addition, role modelling of clinical care from specialist palliative care nurses, has significantly enhanced skills in how to organise and facilitate a palliative care case conference and implement an end of life care pathway.

- Demonstrated improvement in satisfaction from carers in regard to communication particularly with the General Practitioner via attendance at a palliative care case conference. Promotion of the project via resident committees, brochures and newsletters has also provided opportunity to build consumer confidence in how aged care facilities support dying residents and their families.

Contribution to the ongoing development of evidence-based practice in residential aged care

This project has educated participating residential aged care facilities on the importance of evidence based practice. The PA Toolkit contains high quality evidence based resources that will assist all aged care facilities in providing a palliative approach. Designed using the best available evidence they are user friendly and generalisable to facilities regardless of size or location. The development of the Toolkit has provided the opportunity for aged care staff to access and use the best available evidence in proving a palliative approach. Promotion of the caresearch website as a host for project materials and integration of this in staff training will ensure ongoing awareness of new evidence as it is developed.

Conclusions

This project has developed and evaluated a comprehensive evidence based palliative approach in residential aged care. Evaluation has indicated successful changes in clinical practice which has demonstrated improvements in resident care, staff knowledge and family satisfaction. All facilities engaged in the project have indicated that the key processes promoted in CEBPARAC will continue and be embedded as part of routine care.

Recommendations

(1) To directly assist RACFs with implementation of evidence-based practice

- Implementation of evidence based practice requires commitment from all levels of staff and support from management.
- Dedicated education sessions for all levels of staff will assist with implementing evidence based practice.
- Education on any evidence based practice must precede implementation and regular follow up education sessions for new and existing staff will assist with embedding practice change.
- Identification of link nurses (champions) to coordinate and drive practice will assist in embedding practice change. Multiple link nurses, that have this role clearly designated, increase the chance of success.
- Where required seek the assistance of experts external to the organisation – these may be clinical experts or those knowledgeable in evidence based practice.
- Reinforce that evidence based practice will assist the organisation in meeting Standards and in some instances may enhance funding options.

(2) The use of project products and processes

- The final product – The PA Toolkit is available to all participating facilities.
- The PA Toolkit is generalisable to all RACFs and can be produced for a larger audience if required.
- Further development of the supporting educational resources for the RAC EoLCP would enhance implementation.

Part D - Main Report

1 Introduction

1.1 Background

In Australia, 7% of those persons aged over 65 years live in a Residential Aged Care Facility (RACF). Australia, like the rest of the developed world has seen the responsibility for the provision of palliative care increasingly placed upon RACFs. The proportion of separations due to death that occur in RACFs in 2006 was 86.8%¹ with 25% of these residents having a length of stay of less than 26 weeks.

National and local studies have been conducted that indicate the palliative care needs of residents in these settings and have suggested some possible solutions. The first national study concerning the palliative care needs in RACFs was conducted by Maddocks et al in 1996². This national survey identified the need for better assessment and treatment of pain for residents with dementia, more comprehensive advance care planning, education for all staff including general practitioners and increased liaison between RACFs and specialist palliative care services. The first palliative care intervention study in Australia to address these issues was conducted in 1999 in South Australia.³ This study involved the use of 'link nurses' who received training from a specialist palliative care service to become the champions of palliative care within their RACFs. The 'link nurses' were supported by two palliative care clinical nurse consultants who assisted with on-site education for all staff levels and clinical consultations. Staff evaluated the 'link nurse' project positively, reporting improved outcomes for residents and families. Despite this no ongoing funding was available to continue this model. Similar models have also shown to be effective in the United Kingdom (UK)^{4,5} although these studies were focused predominantly on residents with a cancer diagnosis.

Also conducted in South Australia in 2003 an NHMRC study⁶ focused specifically on the palliative care needs of residents with a non-cancer diagnosis. Results indicated that in South Australia, two thirds of RACFs access specialist palliative care services for clinical consultation and education. While results indicated there was improvement in many of the issues raised in the original 1996 study few residents had advance directives and only two thirds of facilities had a palliative care policy. Recommendations from this study included the development and implementation of a structured program of palliative care through the development of policies and procedures and supported by education of staff including the use of a link nurse model which had been successfully trialled in South Australia in 1999.³

These results were partially addressed in a Queensland pilot study⁷ which trialled a multidisciplinary approach to provide palliative care for people with dementia. This study included the use of General Practitioners (GPs) for case conferencing and staff education on the use of the Guidelines for a Palliative Approach (Guidelines). This study showed encouraging results with staff, GPs and families indicating the use of palliative care conferences improved care planning and the education program increased staff knowledge.

Additionally in Queensland the Brisbane South Palliative Care Collaborative (BSPCC)⁸ have received 3 years funding from the Department of Health and Ageing (DoHA) Local Palliative Care Grants Program: Care Planning sub-program to develop, implement and evaluate the effectiveness of a locally adapted end of life care pathway for use specifically in Australian RACFs. The pathway has been adapted from the UK Liverpool Care Pathway and the New South Wales Central Coast Collaborative Pathway. End of life care pathways have been popular in the UK and have demonstrated that documentation is increased following the

introduction of the pathway and symptom burden is significantly reduced⁹ The BSPCC project aims to provide further evidence concerning outcomes for palliative residents and incorporates a 'link nurse model' to facilitate palliative care provision and pathway implementation. Data collection is due to be completed shortly and although no formal statistical analysis has been conducted anecdotal evidence from the BSPCC Palliative Care Nurse Practitioner, in RACF supports the operational value of both the pathway and link nurse model. The pathway will be available for use as part of the model of care proposed in this project.

Other national studies conducted as part of the Caring Communities Grants include the Alzheimer's ACT project improving palliative care for people with dementia and the University of Western Sydney project Palliative Care Dementia Interface: Enhancing Community Capacity. No publications from these studies are currently available.

The Australian government has responded to the recognition of the need to support RACFs in providing palliative care. Under the National Palliative Care Strategy, **the Guidelines for a Palliative Approach in RACFs** were developed. These were supported by **Training modules** for RACF staff and most recently by the program **Engaging GP's Support for the Implementation of Guidelines for a Palliative Approach in Residential Aged Care**. This includes an active learning module and later this year will be further supported by an on-line learning module for GPs. There has also been the establishment of the **Residential Aged Care Palliative Approach Network (RACPAN)**. Despite the availability of these resources in particular the Guidelines, the translation of these and other initiatives into clinical practice has not appeared widespread. Projects conducted to date have preceded the availability of this combined evidence set. A further important factor to consider in these settings is the introduction of the new residential funding instrument the – ACFI. This instrument has specific criteria by which RACFs claim for palliative care and pain management. The model proposed in this project will ensure that RACFs are well equipped to claim reimbursement for the care required for their residents.

The purpose of this project is to synthesise and utilise this comprehensive body of evidence in addition to being responsive to the dynamic aged care environment to support the provision of palliative care in RACFs.

Aims and objectives:

The aim of this project was to implement and evaluate a comprehensive evidence based palliative approach in residential aged care.

The objectives were to:

1. Translate existing evidence based guidelines (palliative care and pain management) into policy and practice (including documentation).
2. Provide education to all nursing and care staff at all levels working in the RACFs using existing training materials.
3. Establish, train and support link nurses in each RACF.
4. Promote the use of existing GP on-line training modules to support GPs in providing a palliative approach to residents in their care.
5. Implement the BSPCC Residential Aged Care End-of-life Care Pathway (RAC EoLCP) for residents requiring terminal care.
6. Develop a palliative care case conferencing learning resource (DVD and hard copy) for residents and family members, nursing staff and GPs.
7. Develop from existing training modules a self-directed learning module for Link nurses.

This project met key Encouraging Best Practice in Residential Aged Care (EBPRAC) Program objectives, including:

1. Improvements in clinical care

2. Opportunities for aged care clinicians to develop and enhance their knowledge and skills
3. Support staff to access and use the best available evidence in everyday practice
4. Clearer industry focus on improvements to clinical care
5. Wide dissemination of proven best practice in clinical care
6. Develop national clinical or educational resources and evidence summaries that support evidence-based practice in aged care and are able to guide the ongoing development of accreditation standards
7. Build consumer confidence in the aged care facilities involved in EBPRAC

Key priority areas were met as follows:

a. Improving quality of clinical care for residents in Australian Government funded aged care homes taking into account resident preferences;

This project was focused on improving the clinical palliative care for residents. Palliative care is person-centred and seeks to provide physical, social, psychological and spiritual needs of the individual with a life-limiting illness including support for families. A key feature of the model is the palliative care case conference for each resident and family. This provided the opportunity for either the resident themselves or a family member to contribute to care planning and to ensure resident preferences are documented and upheld.

b. Communication of the changes required as part of this project to the residents and their families;

Communication between residents, families, staff and consortium members was critical to the success of the project. All residents' and families specifically participating in the project were fully informed and consent obtained. Other resident and families not specifically engaged with the project were made aware the project was being conducted by the use of summary newsletters distributed to each facility. For RACFs where a resident committee was in place a member of the consortium team provided information to the committee.

c. Implementation of change management processes across all levels of staff to ensure that clinical best practice is accepted and informs care delivery; and

As the project team included representatives from the services the model of implementation was based on a collaborative learning approach. In each facility review meetings with nursing and care staff were conducted monthly to ensure that the implementation was specific to the needs of the individual residents and their families, cognisant of local issues and particularly of cultural issues specific to the service.

d. Improving clinical capacity and staff skills through a multi-disciplinary approach.

Key to the delivery of palliative care in RACFs was the involvement of the multidisciplinary team. This varied depending on the size of the facility but included GPs, nursing and care staff and allied health professionals. A key component of this model was the use of the multidisciplinary case conferences and the RAC EoLCP both which are multidisciplinary care processes. Medicare items were available for GPs to claim for conducting or attending a case conference in RACFs providing incentive for GPs.

1.2 The nature of the change in practice

The evidence utilised in this study included:

1. Guidelines for a Palliative Approach in Residential Aged Care – Enhanced Version – May 2006 (and related training modules): The guidelines can be downloaded from the National Health and Medical Research Council website: www.nhmrc.gov.au or the Department of Health and Ageing website: www.health.gov.au/palliativecare. These guidelines will herewith be referred to as the APRAC guidelines.

2. Pain in Residential Aged Care Facilities: Management Strategies – August 2005: The guidelines can be downloaded from the Australian Pain Society website: www.apsoc.org.au. These guidelines will herewith be referred to as the APS guidelines.
3. RACGP's online education portal www.gplearning.com.au/, specifically: Advance care planning for general practitioners (Category 2 – 4 points); Palliative care in aged care homes (Category 2 – 2 points); Palliative care in aged care homes – mini-cases (Category 2 – 3 points).
4. Brisbane South Palliative Care Collaborative – Residential Aged Care End of Life Care Pathway (RAC EoLCP): This tool can be downloaded at the Queensland Health website: http://www.health.qld.gov.au/cpcpre/eol_pthwys.asp

During the development phase, other evidence-based guidelines were reviewed and included if a deficit was noted. These guidelines included:

- Clinical Practice Guidelines for the Management of Delirium in Older People (October, 2006). Available online at: www.health.vic.gov.au/acute-agedcare.
- Royal Nurses Association of Ontario (RNAO) Nursing best practice guidelines: Screening for delirium, dementia and depressions in older adults (November, 2003). Available online at (access date June, 2009): www.rnao.org/bestpractices/PDF/BPG_DDD.pdf.
- Palliative Care Australia. Multicultural Palliative Care Guidelines (1999). Can be downloaded at: <http://www.palliativecare.org.au/Portals/46/resources/MulticulturalGuidelines.pdf>

Note: The APRAC guidelines were scheduled to be reviewed in 2010.

1.3 Context

The Comprehensive Evidenced-Based Palliative Approach in Residential Aged Care (CEBPARAC) project worked with nine RACFs, across four states (New South Wales, Queensland, South Australia and Western Australia):

1. Amaroo Aged Care Service (Blue Care), Tweed Heads, New South Wales
2. Iona Nursing Centre (Blue Care), Kenmore, Queensland
3. Redland Residential Care (Queensland Health), Cleveland, Queensland
4. Moreton Bay Nursing Care Unit (Queensland Health), Wynnum West, Queensland
5. Miroma (Padman Health Services), Daw Park, South Australia
6. Skyline (Padman Health Services, Flagstaff Hill, South Australia
7. Boandik Lodge, Mt Gambier, South Australia
8. The Cove (Brightwater), Mandurah, Western Australia
9. The Oaks (Brightwater), Waikiki, Western Australia

Not-for-profit (Blue Care), private (Padman Health Services, Boandik Lodge, and Brightwater) and government-operated (Queensland Health) organisations were represented. Facilities were based in metropolitan (n=5), outer metropolitan (n=2), and regional areas (n=2) (see Table 1). Number of beds per facility ranged from 48 to 130 beds. All facilities catered for high care residents with two facilities also caring for low care residents. No facilities reported a significant level of cultural diversity in their residents.

Table 1: Facility information

Name	State	Approved provider number	Regional, remote, outer metropolitan	Cultural diversity	Size of RACF: no. of beds	High care/ low care places
Amaroo Aged Care Services	NSW	5124	Regional	No	101 (20 secure dementia)	High care
Iona Nursing Centre	QLD	5893	Metropolitan	No	60	High care
Redland Residential Care	QLD	5504	Metropolitan	No	128	High care
Moreton Bay Nursing Care Unit	QLD	5432	Metropolitan	No	126	High care
Miroma	SA	6849	Metropolitan	No	50 (18 secure dementia)	High care
Skyline	SA	6191	Metropolitan	No	82 (9 secure dementia)	52 High care 30 Low care
Boandik Lodge	SA	6914	Regional	No	48	High care
The Cove	WA	7240	Outer metropolitan	No	130	42 High care 88 Low care
The Oaks	WA	7282	Outer metropolitan	No	60 (31 secure dementia)	High care

The CEBPARAC intervention was mapped to the *Australian Standards for Aged Care* and *The Standards for Providing Quality Palliative Care for all Australians* (see Table 2).

Table 2: CEBPARAC intervention mapped to Australian Standards

CEBPARAC intervention	Aged Care Accreditation		Palliative Care Standards
	Standard 2	Standard 3	
Outcomes			
Key Processes			
Advance care planning		3.8, 3.9	1, 2
Palliative care case conferences	2.6, 2.9	3.8, 3.9	1, 2
End of life Care Pathway	2.9	3.8, 3.9	1, 2, 6, 8
Clinical Care			
Pain	2.4, 2.6, 2.8, 2.9		6
Dyspnoea	2.4, 2.6, 2.9		6
Nutrition and hydration	2.4, 2.6, 2.9, 2.10		6
Oral care (Terminal phase)	2.4, 2.6, 2.9, 2.15		6
Delirium (Terminal phase)	2.4, 2.6, 2.9		6

Question 12 part 14 of the Aged Care Funding Instrument (ACFI) allows a facility to claim funding for a:

“palliative care program involving end of life care where ongoing care will involve very intensive clinical nursing and /or complex pain management in the residential care setting”.

Funding requirements include:

1. A “directive by CNC/ CNS in pain or palliative care or medical practitioner”. Where CNC (clinical nurse consultant)/ CNS (clinical nurse specialist) is a registered nurse who has at least five years full time equivalent registration experience and approved

post-registration nursing qualifications in the specialty fields of pain and/ or palliative care; AND a

2. Pain assessment

The CEBPARAC project recommended conducting a palliative care case conference with the resident's GP or specialist palliative care nurse involvement. This case conference provided the opportunity to review a resident's palliative care needs and decide whether a palliative care program was required. GP involvement was encouraged by raising awareness relating to the Medicare primary care items 735, 739, 743, 747, 750, and 758 (multidisciplinary case conferences).

2 Methods

2.1 Model for change / implementation

The National Institute for Clinical Studies (NICS) provides recommendations and resources to assist in the implementation of evidence into clinical practice. They recommend the use of the RNAO toolkit for implementation of clinical practice guidelines which provides a six stage toolkit. The following six stages outlined in this toolkit formed the basis of the implementation model.

1. Identification of the evidence
2. Stakeholder identification, assessment and engagement
3. Environmental readiness
4. Use of effective implementation strategies
5. Evaluation of evidence implementation
6. Identification of resource requirements

2.1.1 Identification of the evidence

The evidence-based guidelines utilised in the CEBPARAC are outline in Section 1.2.

2.1.2 Stakeholder identification, assessment and engagement

Stakeholders in this project include internal stakeholders which were staff within each of the RACFs and external stakeholders who included family members, GPs, specialist palliative care services and other health professionals providing support to residents and families or professional support to staff members. Within each organisation the number and nature of the stakeholders differed. At the commencement of the project each organisation completed a stakeholder analysis adapted from the RNAO toolkit.

2.1.3 Environmental readiness

The RNAO toolkit identifies key elements that may affect evidence translation and suggests these may be identified by the use of an environmental audit. This audit included identification of facilitators and barriers with regard to the structure and culture of the organisation, communication systems, leadership, knowledge, skills and attitudes of the target group, processes quality management, available resources and interdisciplinary relationships. This environmental readiness audit was conducted at the same time as the stakeholder analysis and prior to commencement of the model within each RACF.

2.1.4 Use of effective implementation strategies

The NICS guide to successful implementation of evidence has identified that change within a setting is possible when a well designed intervention is used. In particular models of multi-professional collaboration in which multiple interventions are combined are considered more effective than single interventions. CEBPARAC was a multi-professional multifaceted intervention sensitive to the local requirements of the consortium facilities.

The implementation strategies included:

1. Development of policies, procedures and supporting documentation for key domains of palliative care practice.
2. Implementation of existing guidelines for palliative care and pain management.
3. Use of existing palliative care educational material for raising staff knowledge, skills and positive attitudes in regard to providing palliative care.
4. Development of new educational material on case conferences meeting a current knowledge-practice gap.
5. The use of 'link nurses' within each facility to support the implementation process and assist with sustainability.

The centrepiece of the implementation strategy was the translation of the Guidelines which provide the evidence base in which to embed a palliative approach in RACFs. To ensure maximum translation of the guidelines to clinical practice six key domains were identified. Within each of these six domains the relevant guidelines were operationalised. The six domain areas were:

1. Advance care planning
2. Physical symptoms
3. Psychological support
4. Family support
5. Advanced dementia
6. Terminal care

2.1.5 Evaluation of evidence implementation

Evaluation of CEBPARAC is based on the Evaluation and Palliative Care Guide produced for the National Palliative Care Strategy (Eager et al 2004). For details refer to Section 2.5.

2.1.6 Identification of resource requirements

Resources required to implement the CEBPARAC project included funding for nurse back-fill and specialist palliative care nurse support.

2.2 Stakeholder engagement

2.2.1 Project Liaisons and Link Nurses

Each facility identified a Project Liaison (often the Director of Nursing) and one or more Link Nurse/s (depending on the size of the facility). The **Project Liaisons (PLs)** provided a direct link between the RACF and project staff facilitating communication exchange between the two parties. They assisted in the evaluation and audit processes. The **Link Nurses (LNs)** were trained by, and worked with, project staff to implement the palliative approach in their facility. Their efforts to implement the approach in their facility served as a model to other staff. Link Nurses were also encouraged to assist in the education of RACF staff. State project managers were in regular contact with LNs and PLs to assist with recruitment, palliative care case conferences, the RAC EoLCP, and general trouble-shooting.

2.2.2 Education and awareness raising

PLs and LNs attended four Link Nurse training days over the course of the project. Held in each state (the New South Wales facility joined with the Queensland facilities), these sessions educated PLs and LNs on the palliative approach with particular emphasis on advance care planning, palliative care case conferencing and terminal care (including the RAC EoLCP and medications). This forum also provided an opportunity to feed back CEBPARAC results and gain PL and LN views on the CEBPARAC toolkit and implementation process. Participants had the opportunity to share their successes and brainstorm any difficulties they faced in facilitating the palliative approach. The final training day included discussions on ongoing sustainability within their facilities, as well as a seminar on self-care in palliative care (a topic requested by a number of PLs and LNs). Each training day was attended by the state project manager and the specialist palliative care nurse consultant. Link Nurse training day agendas are included in Appendix 1.

Each facility received at least three hours of staff education (nurses and care staff). Three core topics were covered: Topic 1: Introduction to a palliative approach; Topic 2: Palliative care case conferencing; and Topic 3: Terminal care and the RAC EoLCP. These sessions were delivered by the specialist palliative care nurse consultant. Additional education was provided to facilities on request.

Monthly reviews were conducted to provide further education to facility staff. Each month the specialist palliative care nurse visited each facility to review residents recruited to the CEBPARAC project. Facility nursing and care staff were encouraged to attend these interactive, educational sessions. Palliative care case conference outcomes and actions were reviewed, and care plans discussed. The resident's current health status was assessed and goals set.

The CEBPARAC project developed several publications to increase awareness of the project. A project brochure was developed outlining the project and the palliative approach. Two versions were developed: one targeting health professionals (including GPs and allied health) and one written for residents and family. These brochures are included in Appendix 2. Project newsletters were printed and circulated to each facility. These newsletters were also mailed to the families of recruited residents and GPs. An example is included in Appendix 3. Several e-newsletters were sent out to motivate and educate PLs and LNs. Each newsletter featured a different evidence-based assessment tool, provided clinical discussion, reviewed an article from the research literature, provided key project reminders and advertised relevant conferences and other key dates. A sample e-newsletter is included in Appendix 4.

CareSearch (www.caresearch.com.au) hosted project webpages. Brochures and newsletter could be downloaded. There was an intranet section where PLs and LNs could access toolkit materials.

Teleconferences were held with at least one representative from each facility to facilitate major project milestones (e.g., commencing recruitment). The CEBPARAC project also invested in a dedicated day for PLs and Project Management Staff to meet and discuss project implementation, following on from the 2009 DoHA Melbourne meeting. Project managers also went to staff meetings at each facility to explain and promote the project. Some resident meetings were also attended, although time did not permit complete coverage of this option.

Cognitively-able residents were actively consented into this project and encouraged to participate in case conferences. Families participating in the study were also actively

consented by the project manager and provided with an information sheet. Families were invited to attend their family member's palliative care case conference.

All GPs connected with the facility were provided with written information on the project. This information outlined the project; invited their participation in palliative care case conferences and the RAC EoLCP; and provided information on Medicare reimbursements and on-line palliative care training. In some cases the project manager was able to meet with GPs face-to-face to discuss the project.

2.3 Partnerships

The CEBPARAC project supported the development of partnerships with local specialist palliative care services, when these did not currently exist and promoted those that did.

2.4 Governance

The project was led by Associate Professor Deborah Parker. Associate Professor Parker is an international expert in aged care palliative care in RACFs and is based at the University of Queensland/ Blue Care Research and Practice Development Centre (RPDC). **The Project Management Team**, consisting of representatives from each state, was responsible for the day-to-day management of the project and met monthly by teleconference. **The Consortium Team** refers to the project liaison officers identified by each residential aged care facility. Consortium members liaised with the relevant project management team state representatives. **The Clinical Team** refers to the specialist palliative care nurses and link nurses. **A Reference group** was also formed to oversee the project and assist with project implementation. Members of the reference group were chosen for their expertise in palliative care, aged care, pain management, and case conferencing. Reference group meetings were held approximately three times a year via teleconference.

The senior project manager (PM) was located in Queensland and based at the RPDC, the South Australia PM was based at the Southern Adelaide Palliative Care Service and the Western Australia PM at the Cancer and Palliative Care Network. The work of the PM at RPDC was the overall co-ordination of the project. They were assisted by an administrative/finance person who provided project support for all states. The Queensland project team were responsible for the RAC EoLCP documentation and implementation. The South Australia project team were specifically responsible for the case-conferencing learning resource with assistance from the Western Australia project team. This demarcation built on the expertise of each of the partners within these geographical boundaries. The PMs in each state were responsible for baseline and post model collection. The consortium team members worked locally with each state project team members to ensure local applicability. Each state team ensured communication with residents and families occurred at the local level.

Financial management of the project was the responsibility of the RPDC supported by the finance department of the University of Queensland. Monthly reports to the RPDC cost centre project account were available from the on-line finance system at University of Queensland.

Strategies to ensure appropriate expenditure included:

1. A dedicated administrative/finance project officer
2. Monthly budget reconciliation
3. Budget status reports tabled at project meetings
4. Appropriate and limited financial delegations
5. Journal reporting completed and actioned
6. Audited financial statements as per DoHA contract
7. Subcontracts between RPDC and each consortium member

2.5 Evaluation methods

Pre-implementation assessment of RACFs

In this phase of the project, a pre-implementation assessment of each of the participating RACFs was undertaken to clarify who were the main stakeholders and what key elements within each RACF would affect the implementation of a new evidence-based model of palliative care. The NICS recommends the use of the RNAO toolkit to assist with projects seeking to implement evidence based practice. Where appropriate the tools recommended by the RNAO and endorsed by NICS were used in this project.

Specifically, two of these RNAO tools – the Stakeholders Assessment Tool (Appendix 5) and the Environmental Assessment Audit (Appendix 6) were used. The project managers assisted the Care Directors at each RACF in the completion of these tools. This provided a list of potential facilitators and barriers to the implementation of the evidence-based model for each RACF. Where possible steps to address any pre-implementation issues were completed prior to the new model being implemented. In instances where barriers remained, these were documented and monitored throughout the project.

Crucial to this phase of the project was the collection of baseline data regarding current palliative care practice within each RACF. Baseline data included: assessment of carer satisfaction; chart audits; survey of staff knowledge of palliative care practices; and an assessment of current palliative care practices in the RACF.

1. Carer satisfaction

Carer data was collected by telephone interview with bereaved carers of residents deceased in the preceding 12 month period at each RACF. Bereaved carers were either the next of kin or legal guardian. A minimum of three months post death of the resident was set as the contact date. A maximum of 10 phone interviews with bereaved carers from each RACF was the target. The Care Director (or their representative) from each RACF initially contacted the bereaved carer to ascertain their willingness to be contacted by a member of the project team. Initial contact by the project team was by phone whereby the details of the project were explained. Carers interested in participating were then sent an information sheet and consent form. Carers who completed the consent form were then contacted by the relevant state project manager to arrange an interview time.

The telephone interview was structured and based on the Nursing Home Version of the After-Death Bereaved Family Member Interview (Teno et al., 2001). This instrument is designed to be administered by telephone to bereaved carers and is a valid and reliable measure. It is the recommended tool for use in Australia by the National Palliative Care Evaluation Strategy (Eager et al., 2003). It takes approximately 30 minutes to complete (Appendix 7).

2. Chart audits

For carers who completed a telephone interview and agreed and consented, a chart audit (Appendix 8) of the care provided in the week prior to the resident's death was completed by the project team.

2. Staff pre-implementation knowledge

All nursing and care staff in each RACF were asked to complete an assessment of their palliative care knowledge. Surveys were distributed to each staff member by the PLs/LNs and staff were asked to complete them and return them to a sealed box provided in the RACF. No identification of staff was required for these surveys. Return of the survey implied

consent. The survey is based on the Palliative Care Providers Evaluation Tool 2.1 (Appendix 9) provided as part of the National Palliative Care Evaluation Toolkit (Eagar et al., 2003).

3. Audit of current palliative care practice

The project managers assisted the Care Directors to complete an assessment of current palliative care practice in the RACF. This was done using the Palliative Care Service Assessment Evaluation Tool 3.1 (Appendix 10) provided as part of the National Palliative Care Evaluation Toolkit (Eagar et al., 2003).

Post-implementation assessment of RACFs

The evaluation phase utilised the same data collection tools as described in the pre-implementation phase. This allowed for comparison pre- and post-implementation.

References

Eagar K, Senior K, Fildes D, Quinsey K, Owen A, Yeatman A, Gordon R and Posner N 2003. The Palliative Care Evaluation Toolkit: A compendium of tools to aid in the evaluation of palliative care projects. Centre for Health Service Development, University of Wollongong.
Teno JM, Claridge B, Casey V, Edgman-Levitan S, Fowler J.: 2001 Validation of Toolkit After-Death Bereaved Family Member Interview. J Pain Symptom Management Sep;22(3):752-8

3 Results

3.1 Process

3.1.1 Stakeholder analysis and environmental readiness

The stakeholder analysis and environmental readiness assessment were conducted with one or two informants from each of the nine facilities (usually this was the Care Director/ Director of Nursing, sometimes with a link nurse).

Stakeholder analysis:

Table 3: Stakeholder analysis outcomes

Stakeholder	Nature of vested interest	Management strategies	Influence	Support
Administration/ Management	Meeting standards/ criteria Obtaining more ACFI money Roll-out to other sites Centres of excellence, raise public profile Resident-focused Lifting profile of aged care nursing	Feedback (plans, outcomes) Promote benefits for organisation	None, Low, High	Irrelevant, Low, High
DON/ Care Manager	Will be facilitating the changes that arise from the project Role model to staff Clinical governance of care provided Ensure clinical needs are met for residents; family satisfaction with service Interested in good evidence Appreciate extra resources	Feedback/ communication/ regular contact Support	High	High
Clinical educator	Key resource for facility in providing palliative care Disseminate knowledge and provide skills training; involved in education roll-out if project successful Non-clinical role allows a 'bigger picture', thus perhaps more objective Expect link nurses to help with in-house training	Flexible materials targeting levels of nursing Feedback, communication, early notice, involve in process	Mod, High	High
Quality assurance staff	Project will provide assistance with accreditation and quality activities Palliative care is on continuous improvement schedule	Feedback on potential impact on facility QI processes Keep in the loop	Low, Mod, High	High
Specialist Palliative Care Services	Clinical resource for technical information – rarely for symptom management Could increase or reduce involvement	Communication	Low (if at all), Mod	High
GPs	Symptom management (primarily medication); some family support; care planning Assist with Advance Health Directive (AHD)	Communication from project Emphasise 'wins' after changes made Reinforce Medicare rebates Education Can change GP if not cooperative Influenced by increased knowledge and confidence of RNs in RACF	Low, High	Dismissive, Varying, High

Stakeholder	Nature of vested interest	Management strategies	Influence	Support
RNs	<p>Their attitude affects overall outcomes for residents</p> <p>Try to keep up with evidence – time is enemy</p> <p>Direct care provider and have coordinating role</p> <p>Benefit from better coordination and planning tools for care provisions</p> <p>No expressions of interest overtly – low initiative on learning or care planning</p> <p>Implications of part-time RNs</p> <p>If see the benefit for resident, RNs will support</p>	<p>Need to understand palliative approach – not all currently do</p> <p>Active engagement</p> <p>Acknowledge knowledge, skills and experience they bring to project</p> <p>Feedback needs to be constructive and non-threatening</p> <p>Ongoing feedback rather than waiting until end of project</p> <p>Provide educational component</p> <p>Emphasise clinical support available; Communicate benefits</p> <p>Communication and early notice</p> <p>Respond to structure and consistency -> prefer “singing from the same song book”</p> <p>Interactive education is good but time restrictions</p>	<p>Low (ENs drive care),</p> <p>Mod, High</p>	<p>Varying,</p> <p>High</p>
EENs/ ENs	<p>High PC focus – ex-carers</p> <p>Drive care</p> <p>Dominant in terms of presence/hours worked</p> <p>Sceptical – just another task to be undertaken</p>	<p>Utilise current skills and knowledge</p> <p>Regular communication, feedback and education (pitch education at their level)</p> <p>Monitor that “they have it”</p>	<p>Mod, High</p>	<p>High</p>
AINs/ Care workers	<p>Primary hands-on care delivery: very resident-focused</p> <p>Do majority of supportive care</p> <p>Often know more about the resident than the RN</p> <p>Often request education re PC eg “what to say” to grieving relative</p> <p>Being the best is important</p>	<p>Give them a role – but problem – need to hold them back!</p> <p>Encouragement (“bottom of the food chain”)</p> <p>Information, communication and education (pitched at their level)</p> <p>Take lead from RNs/ENs</p> <p>Respond to structure and support</p>	<p>Low,</p> <p>Mod, High</p>	<p>Varying,</p> <p>High</p>
Families/ Residents	<p>Recipient of care</p> <p>Confidence in appropriate care being delivered to them; reassurance that loved one is being well cared for</p> <p>Consumer – “expect the best”</p> <p>Often enquire about the need to transfer to hospital</p> <p>OK to discuss ACP – “they know the score”</p>	<p>Education: awareness of palliative care is low</p> <p>Communication; Keep information simple – no jargon; Newsletters/ Resident meetings; Benefit from explanation</p> <p>Support</p>	<p>Varying</p> <p>Low, High</p>	<p>Varying,</p> <p>High</p>

Environmental readiness:

- Structure
 - Delegated authority depending on level of importance of decisions
 - DON liaises with other staff as required but makes final decision
 - Units make own decisions on day-to-day operations but there are overall systems that are facility wide
- Workplace culture
 - Resident-focused in principle – some individuals more task-focused

- Evidence based practice is not in the language of facility staff but this is improving
- May reject if not congruent with own attitudes
- One facility stresses having “scholarly approach” to practice
- Desire to be market leaders/ Pride in organisation
- Change is challenging – evidence, right approach, good care, resident-focused, support
- Communication
 - Multiple methods: Staff meetings (including interdisciplinary team meetings), handovers, quality systems, case notes, committees, memos, notice boards, communication books, newsletters, email
 - Open-door policy
- Leadership
 - Support evidence-based practice
- Knowledge, skills and attitudes
 - Have knowledge but always room for improvement
 - Positive attitude to new initiatives when it comes to resident outcomes
- Commitment to quality management
 - Quality audits conducted
 - Aged care standards
 - Quality control managers
- Interdisciplinary relationships
 - Each is aware of their specific role
 - Difficult to access GPs
 - Good relationships with allied health (IDT meetings, communication books)

3.1.2 Implementation

During implementation the model of evidence-based care was incorporated into clinical practice. Integral to this phase was the development, in consultation with clinical staff, of key domains of palliative care and documentation and resources to support these domains. Also included was the training of nursing and care staff. The specialist palliative care nurse consultants provided clinical support to the RACF staff and GPs in each RACF during the implementation of the new model. The box below provides a summary of the Toolkit used for implementation.

Box 1: Initial CEBPARAC resources

A Toolkit of resources was developed for implementation. This included:

Six domains of care:

- (1) Family care
- (2) Psychological care of the resident
- (3) Physical symptoms
- (4) Dementia
- (5) Advance care planning
- (6) Terminal care

Each domain of care was mapped against:

- (1) Aged Care Accreditation Standards
- (2) Palliative Care Australia Standards
- (3) Aged Care Funding Instrument
- (4) Evidence based Assessment and Management Strategies (from the guidelines)
- (5) Audit tools

Educational products.

- (1) 2 DVDs:
 - “All on the same page” (Developed for the project)
 - “Suiting the needs”(Existing resource from Palliative Care Australia)

- (2) A link nurse self-directed learning package
- (3) Educational flip charts: mapped to the six domains of care and targeted care staff.
- (4) GP online training modules (Existing resource)
- (5) Brochure – Now What? Understand Grief (Existing resource)
- (6) Brochure – Understanding the Dying Process (Existing resource)
- (7) Guidelines for a Palliative Approach in Residential Aged Care – Enhanced **Version** (Existing resource)
- (8) Australian Pain Society Guidelines (Existing resource)

Training of RACF staff

Training on the implementation of the new evidence-based model of care was provided for nursing and care staff. The facilities requested varying session lengths (see Table 4). Four facilities released staff for 3-4 hour sessions (so each topic was covered in the one session). The remaining facilities could only release staff for 30-60 minutes sessions (so each topic had to be covered in a separate session). These differences existed despite back-fill paid to all facilities for staff attendance. Further some facilities requested that sessions take place in each unit. Also two facilities requested sessions for night staff. Consequently, the number of sessions conducted at each facility ranged from one to nine sessions. The total hours of core education training time at each facility ranged from three to nine hours. Staff attendance at each of the topics were as follows: Topic 1 “Introduction to a palliative approach” (22-72%); Topic 2 “Palliative care case conferencing” (4-72%); Topic 3 “Terminal care and the RAC EoLCP” (17-72%). All levels of staff (RNs, ENs, and CWs) were represented at each session. Additional education was provided to facilities on request. Requested topics included pain assessment and management, medications, mouth care, and management of dyspnoea. Nine extra sessions were conducted across two facilities. An additional session was held for palliative care volunteers in one of these facilities.

Table 4: Summary of facility education

Facility*	Seminar topic	Number of sessions	Duration of session/s (in mins)	Total number of nursing and care staff	% of total nursing and care staff
Facility 1	1	4	45	8 RN, 7 EN, 17 CW	37
Facility 1	2	1	45	3 RN, 3 EN, 4 CW	12
Facility 1	3	4	30-45	6 RN, 2 EN, 7 CW	17
Facility 2	1, 2, 3	1	180	4 RN, 1 EN, 20 CW	32
Facility 3	1, 2, 3	2	180-240	5 RN, 3 EN, 28 CW	46
Facility 4	1, 2, 3	3	180	21 RN, 4 EN, 24 CW	72
Facility 5	1	2	45	1 RN, 1 EN, 13 CW	22
Facility 5	2	1	45	5 RN, 2 EN, 3 CW	15
Facility 5	3	3	30	1 RN, 1 EN, 19 CW	30
Facility 6	1, 2, 3	2	180	9 RN, 3 EN, 12 CW	51
Facility 7	1, 2, 3	2	180	8 RN, 1 EN, 24 CW	45
Facility 8	1	2	30	5 RN, 1 EN, 8 CW	28
Facility 8	2	1	45	1 RN, 1 CW	4
Facility 8	3	2	30-60	6 RN, 1 EN, 11 CW	36
Facility 9	1	2	45	14 RN, 7 EN, 16 CW	45
Facility 9	2	1	45	4 RN, 3 EN, 2 CW	11
Facility 9	3	2	45	9 RN, 5 EN, 4 CW	22

*Facilities have been de-identified by randomly assigning them a number from 1-9

RN=Registered nurse or clinical nurse; EN=Endorsed enrolled nurse or enrolled nurse; CW=Careworker or assistant-in-nursing

First sessions and/or extended sessions obtained higher attendance rates than the briefer, later sessions. This indicates that we should encourage facilities to invest in a dedicated, extended block of education time to introduce a palliative approach for the facility. If this is

not possible, high attendance rates may be reliant on multiple, small-group sessions (and link nurses may need to take the lead in facilitating these sessions).

Recruitment of residents to trial the new model of care

The new model of care was tested during the implementation phase through the recruitment of residents identified by the Care Director as requiring palliative care. The inclusion criteria to guide the selection of residents who may be suitable for participation is based on the trip wire questions for considering palliative care as provided in the APRAC guidelines. That is:

- A positive response to the question: “Would you be surprised if the resident died within the next six months?”
- If there has been a significant functional or medical decline
- If problems are perceived concerning goals of care around futile treatment (perhaps after an acute event)
- If the resident is transferred or admitted to the RACF specifically for comfort care or palliative care

These questions were used to begin the discussion between the Care Director and project staff as to the possible suitability of a resident to be part of the project. Prior to the resident and/or their family being approached, the resident's GP was consulted by the Care Director for the final clinical decision as to the appropriateness of the resident for palliative care.

For residents where there was agreement between the Care Director, GP and project staff that a resident is suitable for palliative care, the Care Director approached the resident (where possible) and their family/legal guardian to ascertain their willingness to meet a member of the project team. For residents and their family/legal guardian who were willing to consider participation, the project manager made contact, explained the study and gained consent. The target number of residents in this phase is 10 per RACF.

In total 73 residents were recruited across the nine facilities (that is, 6-10 residents per facility). Specifically: Facility 1 (n=9), Facility 2 (n=8), Facility 3 (n=8), Facility 4 (n=8), Facility 5 (n=8), Facility 6 (n=9), Facility 7 (n=10), Facility 8 (n=6), Facility 9 (n=7).

Some PLs and LNs felt the trip wire questions for considering palliative care did not provide enough guidance for deciding a resident had a prognosis of approximately six months. However almost 60% of the residents they recommended for inclusion died within a six month time frame. A further 33% had not reached the six-month mark prior to the conclusion of data collection (1 September 2010). Only 7 residents had passed the six-month mark at the end of data collection. Specifically, 42 (57.5%) of the recruited residents passed away prior to the end of data collection. The median number of days between the palliative care case conference (or initial recruitment if they died prior to the case conference or did not have a case conference) and death was 18 days (IQR=70.5). The range was 1-161 days. For the 31 (42.5%) of residents still living at the end of data collection the median number of days between palliative care case conference (or initial recruitment) and end of data collection was 134 days (IQR=83.0) and the range was 49-259 days.

Participation

Residents (where possible) and family member/s participated in a multidisciplinary palliative care case conference with the GP, nursing and allied health staff of the RACF and a specialist palliative care nurse. The case conference was led by either the specialist palliative care nurse or link nurse/facility nursing staff. At this case conference a palliative care plan was agreed upon. The specialist palliative care nurse provided clinical support to the RACF staff and GP. If during the implementation phase the resident's condition indicated terminal care (last few days of life) was required the resident was commenced on the RAC EoLCP.

Uptake of palliative care case conferences was high: 69/73 (94.5%) recruited residents had a palliative care case conference. GP involvement was excellent – with just over 55% (38/69; 55.1%) of case conferences attended by a GP. Only 5/69 (7.2%) of case conferences had neither a GP nor a specialist palliative care nurse in attendance (face-to-face or by telephone). This has implications for claiming ACFI (Question 12, Complex care, Palliative care) which requires sign off from a GP or a specialist palliative care nurse with at least five years experience should a palliative care program be agreed is required. An RN or EEN from the facility always attended the case conferences with care staff involved in one third (23/69; 33.3%). Families were present at 94.2% (65/69) of the time. Residents participated in just over 20% of the case conferences (14/69; 20.3%). Allied health had the lowest representation, attending only 7/69 (10.1%) of case conferences. Those attending included a physiotherapist, two social workers, a speech pathologist, a diversional therapist and a representative from the Huntington’s Association.

Identification of key stakeholders was a key element to ensure relevant input is provided – i.e. care staff; medical staff; specialist staff, residents and family members. The processes used to engage all stakeholders was considered to be critical. This included the importance of having a pre-conference information sheet completed, a skilled facilitator, well-structured and organised meetings and good communication.

Of the 42 residents who died in the data collection period 28 (66.7%) were commenced on the RAC EoLCP. The number of days residents were on the pathway ranged from 0 to 35 days with a median of 5 days (IQR=10).

3.2 New Resources Developed

Based on link nurse/ project liaison feedback during implementation the educational resources were formatted as follows:

Box 2: Final CEBPARAC Toolkit

The Palliative Approach Toolkit (PA Toolkit) has the following components

Three modules:

- (1) Integrating a palliative approach for managers** (guidelines, standards, ACFI, quality control, staff education, role of link nurse);
- (2) Key processes in a palliative approach** (advance care planning, palliative care case conferences, end of life care pathways); and
- (3) Clinical care** (pain, dyspnoea, nutrition and hydration, mouth care, and delirium. The clinical care modules will break down sections into a “see, say, do, write and review format”.
 - See: Recognition and assessment
 - Say: Report assessment
 - Do: Manage symptoms
 - Write: Document your actions
 - Review: Evaluate and re-assess as necessary

Education products:

- (1) 2 DVDs:**
 - “All on the same page” (Developed by the project)
 - “Suiting the needs”(Existing Palliative Care Australia resource)
- (2) Three self-directed learning packages** (these packages will utilise case studies from the two DVDs):
 - (a) Nurse (RN/EN introduction);
 - (b) Nurse (RN/EN advanced); and

(c) Care staff (Introduction)

(3) A Calendar of Posters that can be rotated to cue key messages of a palliative approach.

(4) Five educational flip charts: The presentations are mapped to the clinical care topics and target care staff.

Also included in the PA Toolkit is a copy of:

(1) Therapeutic Guidelines: Palliative Care version 3 (Existing resource)

(2) Palliative Care Australia Standards (Existing resource)

(3) Brochure – Now What? Understand Grief (Existing resource)

(4) Brochure – Understanding the Dying Process (Existing resource)

(5) Guidelines for a Palliative Approach in Residential Aged Care – **Enhanced Version** (Existing resource)

3.3 Impact

3.3.1 Impact on the use of evidence

3.3.1.1 Chart audits

Chart audits were completed on 83 residents pre-intervention and 73 residents post-intervention. At post-intervention, 31/73 (42.5%) of residents were still living at the time of data collection. The chart audit was slightly revised to address this. Both versions of the chart audit are presented in Appendix 8.

Advance care planning

There were statistically significant increases pre- to post-intervention in:

- documented evidence on the initial admission form for any information regarding end-of-life wishes (55.4 v 72.6%, $\chi^2=4.94$, $p<0.05$)
- documented evidence that relatives or legal guardians were involved in end-of-life discussions (71.1 v 95.7%, $\chi^2=15.85$, $p<0.001$)
- documentation of a palliative care conference (8.4 v 94.5%, $\chi^2=115.21$, $p<0.001$)
- care matching wishes on advance care plan (82.6 v 95.5%, $\chi^2=5.78$, $p<0.05$)

There was a non-significant increase pre- to post-intervention in the completion of a non-legal directive (50.6 v 57.5%, $\chi^2=0.74$, $p=0.39$). Legal advance health directive completions reduced pre- to post-intervention (22.2 v 16.9, $\chi^2=0.68$, $p=0.68$, $p=0.41$ n.s.).

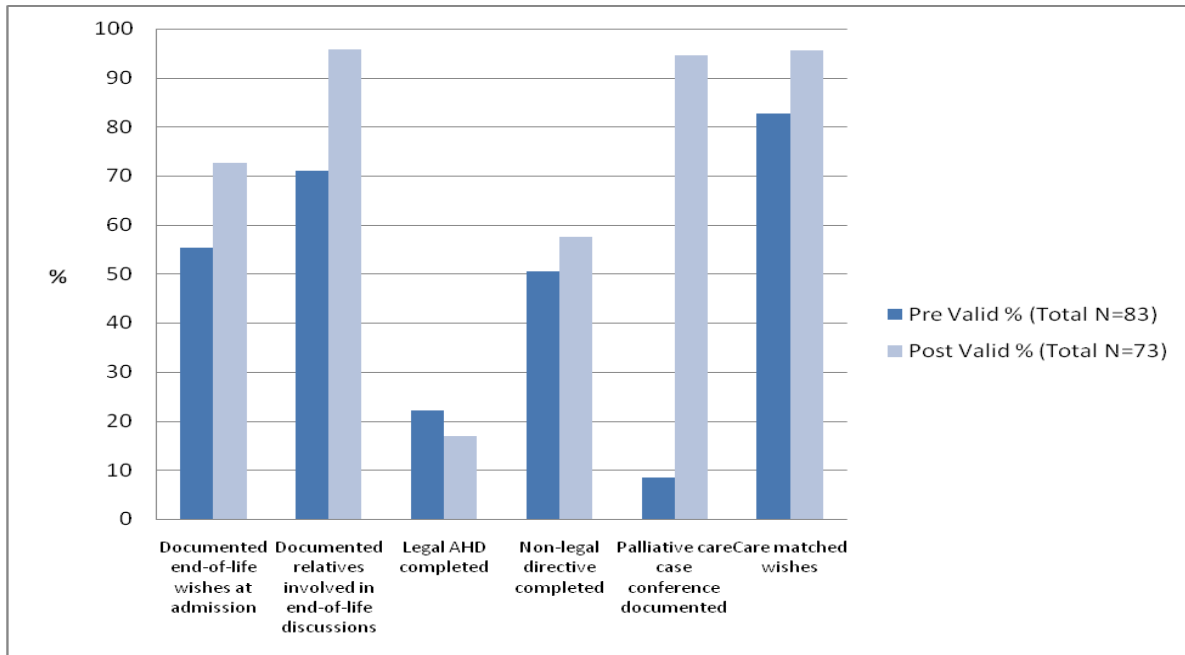


Figure 1: Chart audit outcomes for advance care planning

Pain

Seventy-seven (92.8%) and 65 (89.0%) of residents had pain documented as a symptom at pre- and post-intervention respectively. For those residents with pain documented, there were significant increases pre- to post-intervention in:

- the utilisation of a pain assessment tool (29.9 v 72.3%, $\chi^2=25.40$, $p<0.001$)
- documented evidence that pain was assessed regularly (41.6 v 70.3%, $\chi^2=11.66$, $p=0.001$)
- documented evidence of the effectiveness of non-pharmacological treatment (23.4 v 62.5%, $\chi^2=22.09$, $p<0.001$)

There was a non-significant increase pre- to post-intervention in documented evidence of the effectiveness of pharmacological treatment (63.2 v 76.6%, $\chi^2=2.93$, $p=0.09$).

Of those with pain documented as a symptom, 67 (87.0%) and 62 (95.4%) were on regular analgesia at pre- and post-intervention, respectively. And 66 (85.7%) and 59 (90.8%) were on prn analgesia at pre- and post-intervention, respectively. For those on the respective medications, there were non-significant increases pre- to post-intervention in:

- documented evidence that regular analgesia was effective (56.7 v 64.5%, $\chi^2=0.82$, $p=0.37$)
- documented evidence that the prn analgesia was effective (62.1 v 77.6%, $\chi^2=3.47$, $p=0.06$)

Of those on either regular analgesia or prn analgesia, 92.4% and 98.4% of pre- and post-intervention residents had a bowel management plan (including aperients).

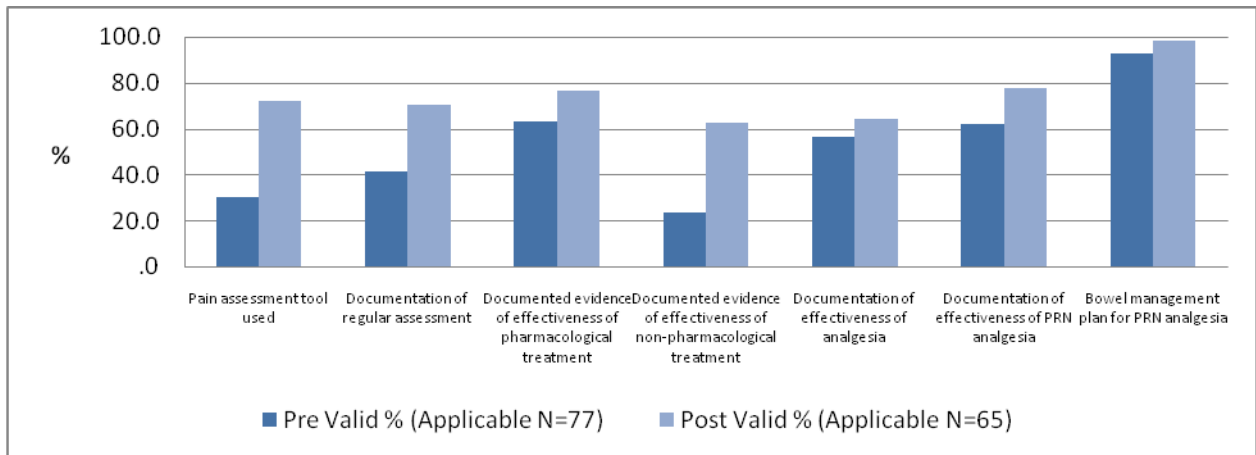


Figure 2: Chart audit outcomes for pain assessment and management

Dyspnoea

Forty-two (50.6%) and 28 (38.9%) of residents had dyspnoea documented as a symptom at pre- and post-intervention, respectively. Of these, 27 (65.9%) and 24 (85.7%) residents were on medication for dyspnoea at pre- and post-intervention, respectively. And 19 (46.3%) and 13 (48.1%) were on oxygen. There were statistically significant increases pre- to post-intervention in the following:

- dyspnoea was assessed using a tool (2.4 v 44.4%, $\chi^2=18.58$, $p<0.001$)
- dyspnoea was assessed regularly (31.7 v 57.1%, $\chi^2=4.42$, $p<0.05$)
- non-pharmacological management strategies were documented (29.3 v 60.7%, $\chi^2=6.75$, $p<0.01$)

The increase in documentation relating to the effectiveness of treatment at post-intervention neared statistical significance (46.3 v 67.9%; $\chi^2=3.11$, $p=0.08$).

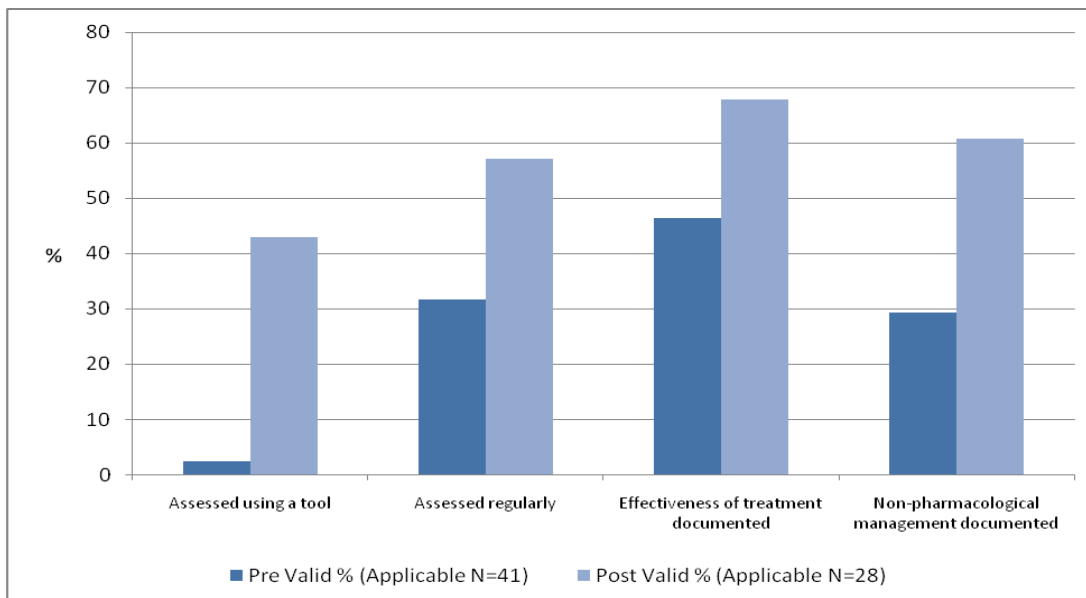


Figure 3: Chart audit outcomes for dyspnoea assessment and management

Nutrition and hydration

Table 5 outlines the prevalence of nutrition and hydration related issues for residents pre- and post-intervention.

Table 5: Prevalence of nutrition and hydration related issues

Issue	Pre	Post
The resident had issues concerning nutrition documented	63 (75.9%)	51 (69.9%)
The resident had issues concerning hydration documented	39 (47.0%)	44 (62.0%)
Dysphagia was documented as a symptom	52 (62.7%)	35 (48.6%)
Resident was commenced on artificial hydration	6 (11.8%)	1 (2.9%)
Resident was commenced on artificial nutrition	3 (6.3%)	1 (2.9%)

For those with dysphagia documented as a symptom, there was a significant increase pre- to post-intervention in the regular assessment of dysphagia (50.0 v 82.4%, $\chi^2=9.21$, $p=0.002$). There were non-significant increases in the:

- referrals to other health professionals made to assess dysphagia (51.9 v 55.9%, $\chi^2=0.13$, $p=0.72$)
- documented effectiveness of treatment (60.8 v 76.5%, $\chi^2=2.27$, $p=0.13$)

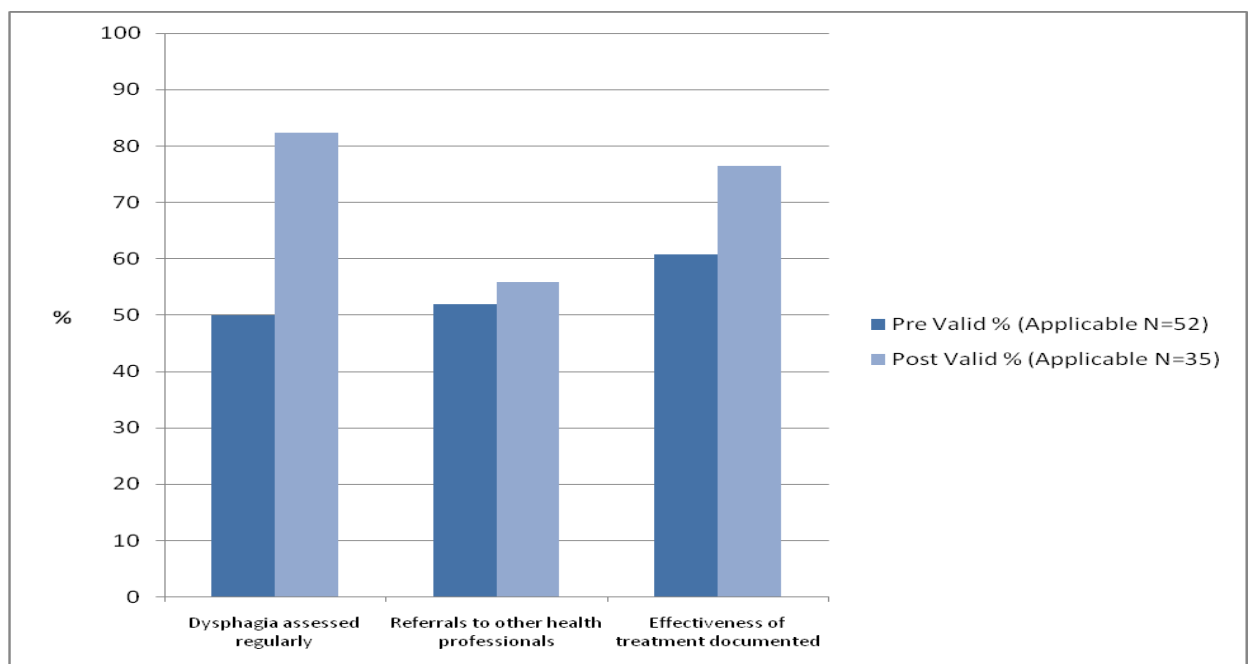


Figure 4: Chart audit outcomes for dysphagia assessment and management

Mouth care

There were significant increases pre- to post-intervention in:

- completed oral health assessments (39.8 v 63.0%, $\chi^2=8.40$, $p=0.004$)
- documented evidence of an oral health care plan (61.4 v 91.8%, $\chi^2=19.40$, $p<0.001$)
- documented evidence of the effectiveness of the oral health care plan (13.3 v 40.8%, $\chi^2= 15.15$, $p=<0.001$)

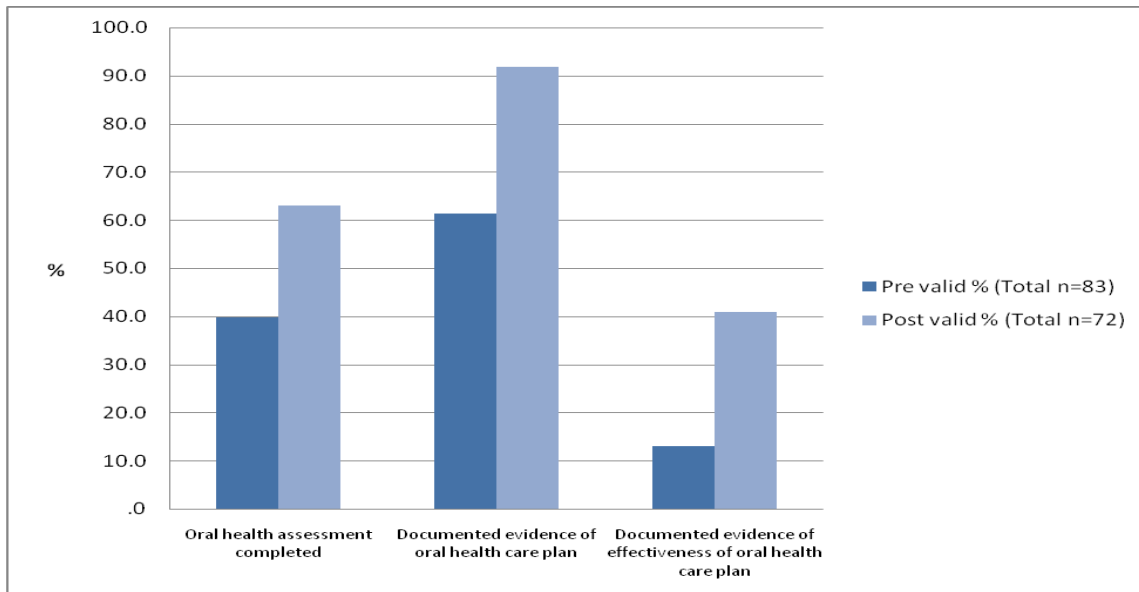


Figure 5: Chart audit outcomes for oral health assessment and management

Infection/ fever

Infection/fever was documented as a symptom in 33 (39.8%) residents pre-intervention and 17 (23.6%) of residents post-intervention. There were non-significant increases in the:

- regular assessment of infection/fever (63.3 v 75.0%, $\chi^2=0.65$, $p=0.42$)
- antibiotics given with a palliative intent (43.3 v 71.4%, $\chi^2=3.02$, $p=0.08$)

There was non-significant decrease pre- to post-intervention in the documentation of treatment effectiveness (73.3 v 57.1%, $p=0.32$).

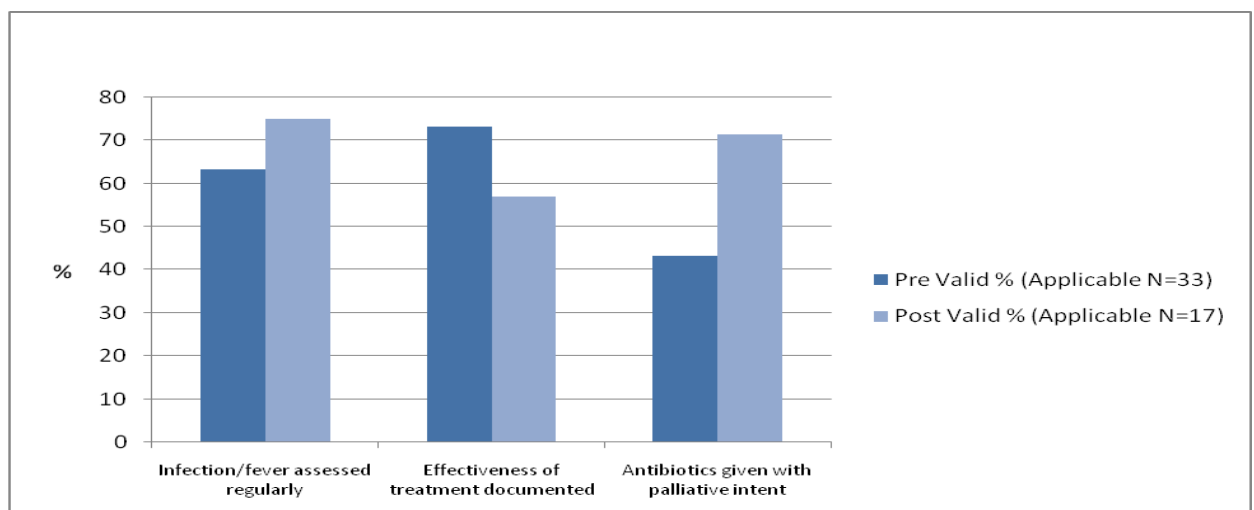


Figure 6: Chart audit outcomes for assessment and management of infection/fever

Delirium

Delirium was documented as a symptom in 14 (16.9%) of pre-intervention residents and 6 (8.3%) of post-intervention residents. Of those with documented delirium, there were no significant differences identified pre- to post- intervention for the:

- administration of the Confusion Assessment Method (CAM) (8.3 v 50.0%, $p=0.08$)
- ordering of a prn anti-psychotic (27.3 v 66.7%, $p=0.16$)
- documentation of treatment effectiveness (54.5 v 50.0%, $p=1.00$)

Note: because of small numbers exact results are provided and should be interpreted with caution.

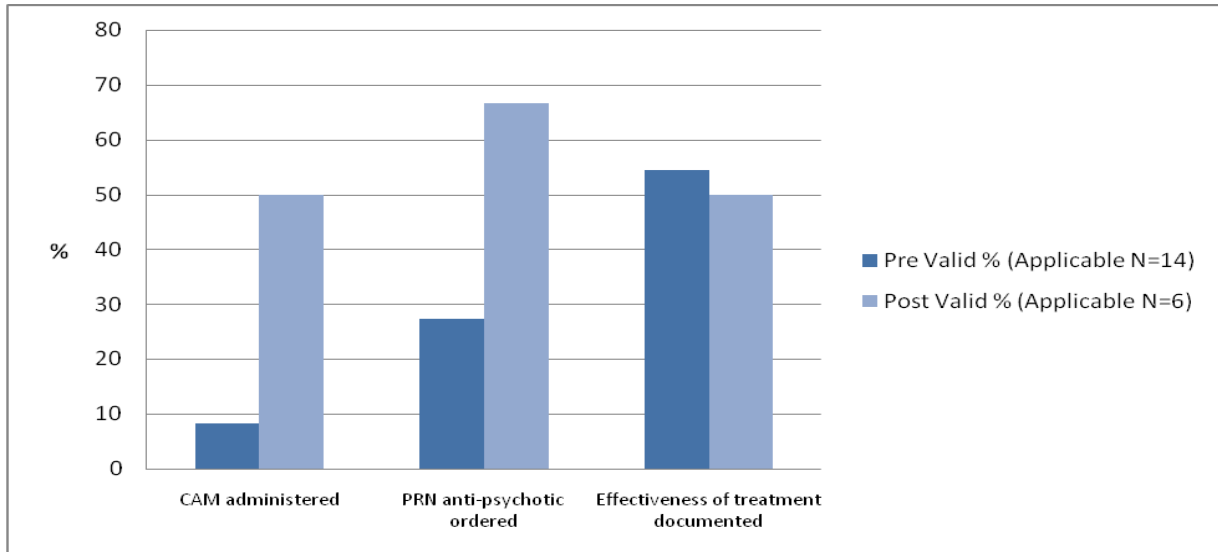


Figure 7: Chart audit outcomes for the assessment and management of delirium

Depression

Depression was documented as a symptom in 31 (37.3%) and 31 (43.1%) of residents at pre- and post-intervention, respectively. For those with depression documented, there were significant increases from pre- to post-intervention in the:

- the ordering of anti-depressants (56.7 v 80.6%, $\chi^2=4.09$, $p<0.05$)
- evidence of non-pharmacological treatment plan (20.0 v 56.7%, $\chi^2=8.53$, $p=0.003$)

There was a non-significant increase in the documentation of anti-depressant effectiveness (29.4 v 56.0%, $\chi^2=2.89$, $p=0.09$). Finally there was no significant change in the use of the Modified Cornell Scale for Depression (64.5 v 61.3%, $\chi^2=0.07$, $p=0.79$).

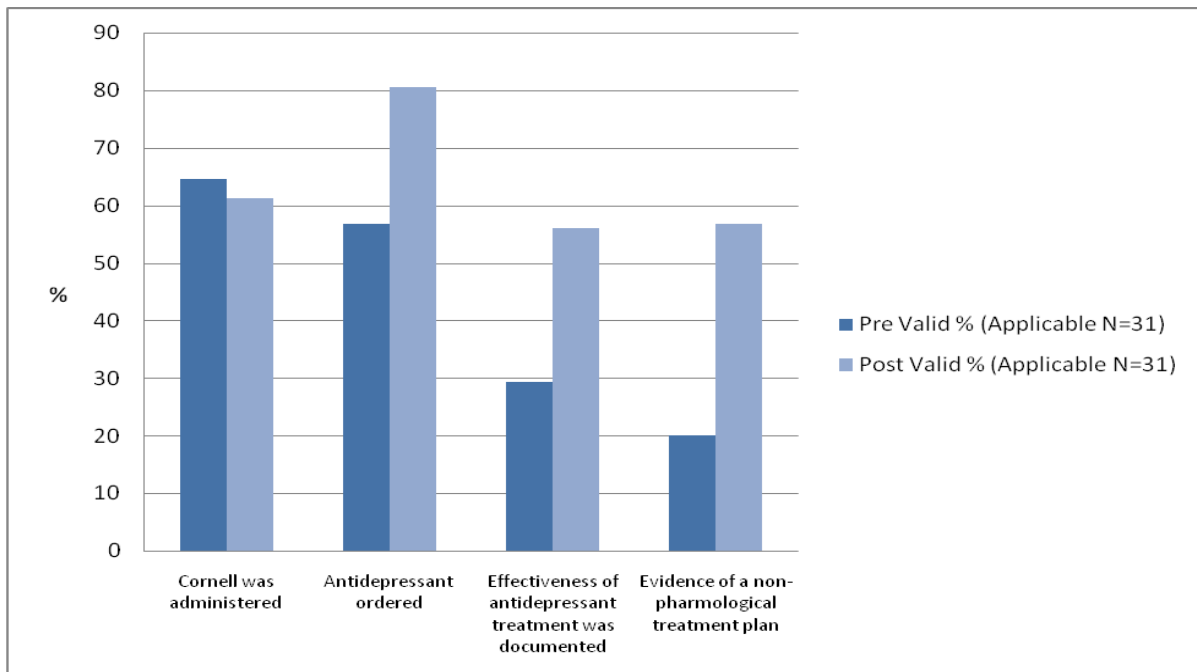


Figure 8: Chart audit outcomes for assessment and management of depression

Communication and cultural care

There were non-significant increases from pre- to post-intervention in the:

- documentation of family relationships (74.7 v 78.1%, $\chi^2=0.25$, $p=0.62$)
- documentation of cultural issues (31.0 v 41.2%, $\chi^2=1.57$, $p=0.21$)

For the residents who had died at the time of chart audit (at post-intervention 42.5% of residents were still living), there were statistically significant increases in:

- assessments of bereavement risk prior to of following the resident's death (0.0 v 39.0%, $\chi^2= 36.79$, $p<0.001$)
- informing family of the tasks required following the resident's death (4.9 v 42.5%, $\chi^2=26.70$, $p<0.001$)
- documentation of information to family following the death of the resident (3.7 v 28.2%, $p<0.001$)

Documentation of the family being made aware death was imminent also increased (although the result was not significant) (83.1 v 92.7%, $\chi^2=2.12$, $p=0.15$). There was a significant decrease pre- to post-intervention in informing family of the resident's death (98.8 v 90.0%, $p=0.04$).

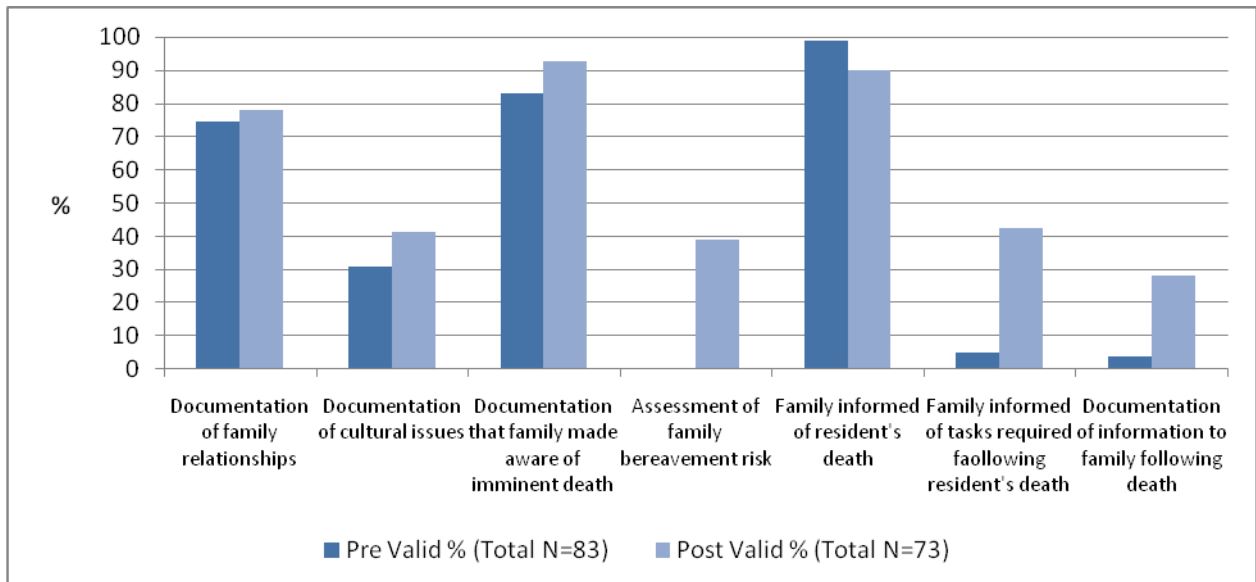


Figure 9: Chart audit outcomes for family and cultural issues

Referrals to other services

There were significant increases pre- to post-intervention in the:

- documentation of consultation by a specialist palliative care service (9.8 v 29.2%, $\chi^2=9.45$, $p=0.002$)
- referral to other specialist services e.g., pain clinic (19.3 v 42.0%, $\chi^2=9.36$, $p=0.002$)

There was a non-significant increase in documentations of referrals to specialist palliative care services (12.2 v 19.4%, $\chi^2=1.53$, $p=0.22$).

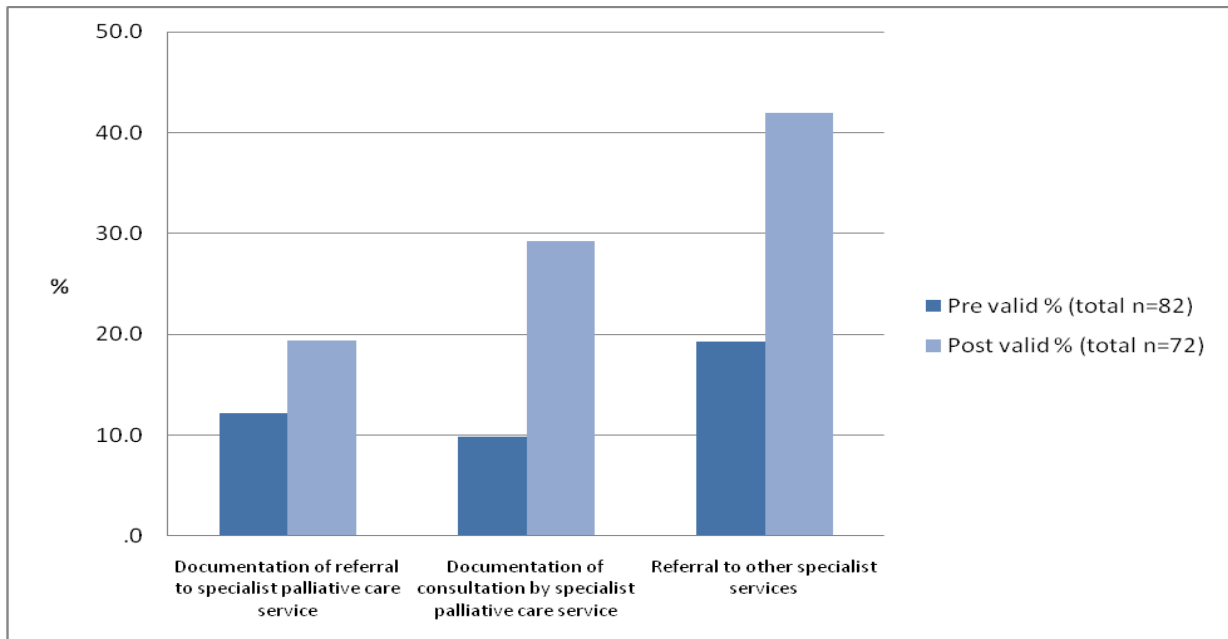


Figure 10: Chart audit outcomes for referrals to other services

Terminal care

There was a significant increase pre- to post-intervention in:

- residents commenced on an end of life care pathway (8.4 v 66.7%, $\chi^2=46.91$, $p<0.001$)
- documentation indicating agreement to commence pathway by the GP and family (21.7 v 84.6%, $\chi^2=37.65$, $p<0.001$)
- assessment of pain minimum of 4 hourly (12.2 v 72.5%, $\chi^2=42.54$, $p<0.001$)
- assessment of nausea and vomiting minimum of 4 hourly (8.1 v 70.0%, $\chi^2=47.52$, $p<0.001$)
- assessment of respiratory symptoms minimum of 4 hourly (10.8 v 70.0, $p<0.001$)
- assessment of agitation and restlessness minimum of 4 hourly (9.5% v 66.7%, $\chi^2=40.43$, $p<0.001$)
- syringe drive check completed minimum of 4 hourly (22.2 v 75.0%, $\chi^2=16.30$, $p<0.001$)
- comfortable position maintained minimum of 4 hourly (35.1 v 85.0%, $\chi^2=25.90$, $p<0.001$)
- mouth care given minimum of 4 hourly (17.6 v 75.0%, $\chi^2=36.46$, $p<0.001$)
- eye care given minimum of 4 hourly (4.1 v 72.5%, $\chi^2=60.25$, $p<0.001$)
- skin care given minimum of 4 hourly (23.0 v 80.0%, $\chi^2=34.46$, $p<0.001$)
- urinary continence care given minimum of 4 hourly (25.7 v 72.5, $\chi^2=23.35$, $p<0.001$)
- bowel care addressed minimum of 4 hourly (3.0 v 72.5%, $\chi^2=60.95$, $p<0.001$)
- psychological support addressed during 24 hours (20.0 v 57.5%, $\chi^2=16.58$, $p<0.001$)
- spiritual, religious, cultural needs/ rituals are facilitated during 24 hours (14.7 v 55.0%; $\chi^2= 20.74$, $p<0.001$)

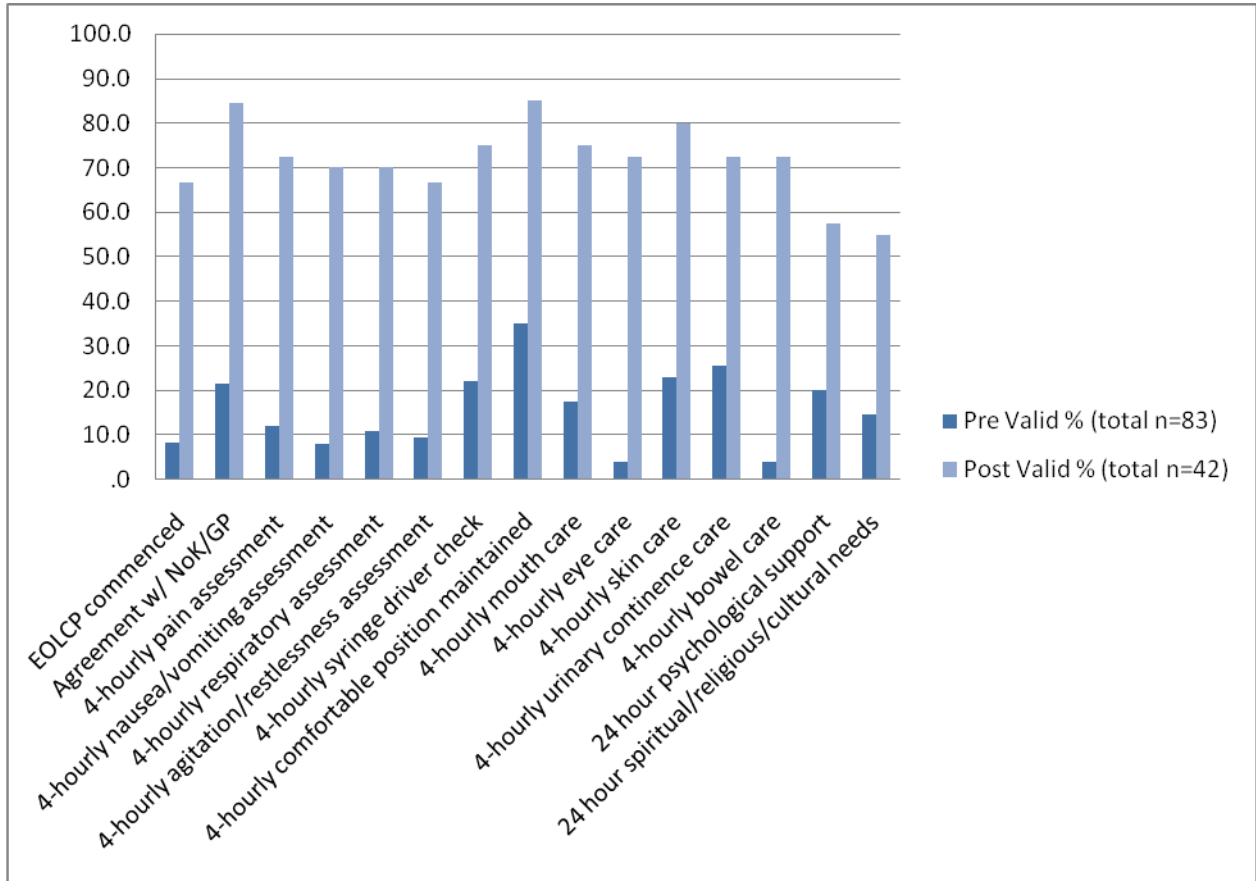


Figure 11: Chart audit outcomes for terminal care

3.3.2 Impact on residents and families

3.3.2.1 Family member interview

Eighty-four next-of-kin were interviewed at baseline utilising the Nursing Home Version of the After-Death Bereaved Family Member Interview (Teno et al., 2001) (see Appendix 7). Of the 73 residents recruited during the intervention phase interviews were conducted with 57 (78.1%) next-of-kin. Reasons for non-participation included: no family or next-of-kin, respondent not wanting to undertake, respondent ill health, not contactable/ not returning messages. Approximately half the residents (49.1%) were still alive at the time of the post-intervention interviews with next-of-kin, and the questionnaire was modified accordingly (see Appendix 7).

Interaction with GP

There was a slight (but not statistically significantly) reduction from pre- to post-intervention in the number of next-of-kin reporting talking with the resident's doctor in the resident's last week (or last month if the resident was still living) (35.7 v 29.8%; $\chi^2=0.5$, $p=0.47$). There was no change in the proportion of people:

- understanding what the doctor was saying (90.0 v 88.2%, $p=1.00$)
- reporting the GP listened to their concerns (96.2 v 93.3%, $p=1.00$)
- reporting the GP gave just the right amount of information (82.4 v 80.9%, $p=1.00$).

There was a slight, non-significant increase in those reporting: the GP never gave confusing or contradictory information about the resident's medical condition (83.3 v 88.2%; $p=1.00$); there was always a doctor in charge of the resident's care (92.5 v 98.2%, $p=0.24$). There was a positive increase, approaching significance, in the proportion of respondents reporting

it was clear to them which doctor was in charge of the resident's care (69.0 v 82.5%, $\chi^2=3.2$, $p=0.07$).

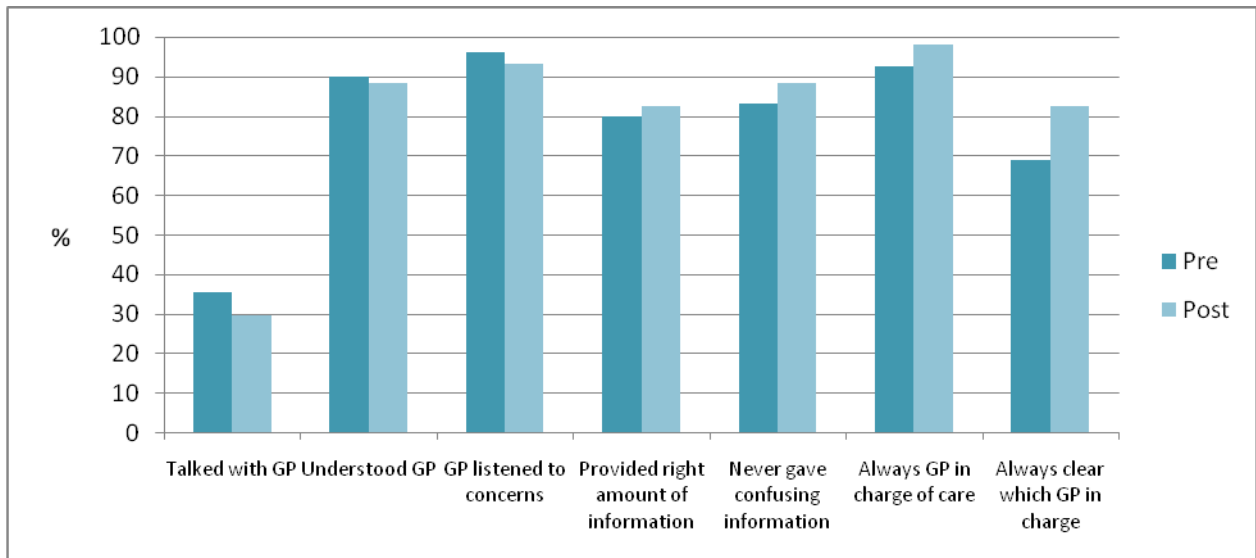


Figure 12: Family member interview outcomes for GP interactions

Advance care planning

According to the next-of-kin, the proportion of residents with specific wishes or plans about the types of medical treatment they did or did not want while dying did not differ between pre- and post-intervention (48.8 v 52.6%, $\chi^2=0.20$, $p=0.66$). For those with specific wishes there were non-significant increases in:

- The GP or medical staff speaking to the resident or family about resident's wishes for medical treatment (80.0 v 86.2%, $\chi^2=0.45$, $p=0.50$)
- GP or medical staff speaking to the resident or family about making sure resident's care was consistent with wishes (70.7 v 86.7%, $\chi^2=2.52$, $p=0.11$)

And no difference pre- to post-intervention in:

- Medical procedures or treatment that happened that were inconsistent with previously stated wishes (14.6 v 16.7%, $p=1.00$).

There were non-significant increases pre- to post-intervention in residents with a:

- signed legal form such as an Enduring Power of Attorney (EPOA) naming someone to make decisions about medical treatment if resident could not speak for him/herself (67.9 v 73.2%, $\chi^2=0.46$, $p=0.50$)
- signed legal form such as an Advance Health Directive (AHD) (20.2 v 25.5%, $\chi^2=0.52$, $p=0.47$)

For those residents with an EPOA or AHD, there was a statistically significant increase in the proportion of respondents/residents discussing these documents with a GP caring for the resident while under care of the RACF (32.8 v 70.3%, $\chi^2=12.75$, $p<0.001$).

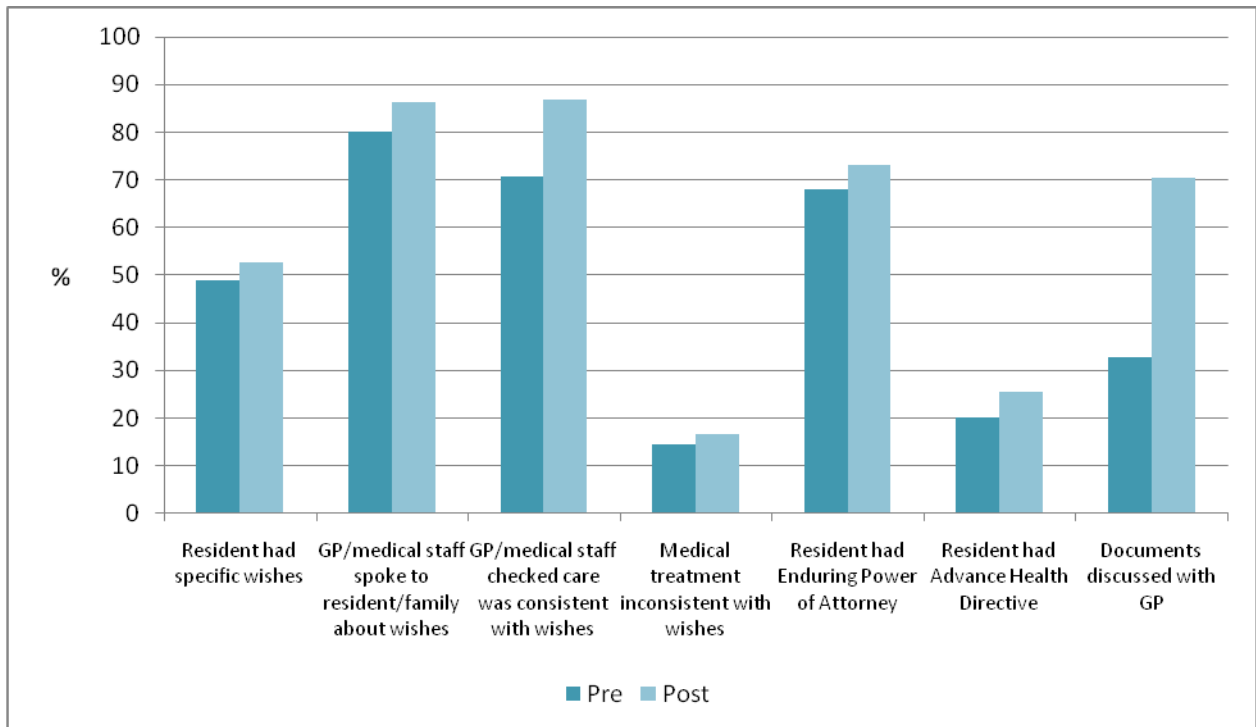


Figure 13: Family member interview outcomes for advance care planning

Symptom management

Fifty-five (87.3%) and 43 (76.8%) pre- and post-intervention residents were on medicines to treat pain. Of those on pain medication, there was no change pre- to post-intervention with respect to the:

- GP or medical staff clearly explaining the treatment plan (78.2 v 81.4%, $\chi^2=0.15$, $p=0.70$).
- Resident receiving the right amount of medication for his/her pain (83.7 v 84.6%, $\chi^2=0.01$, $p=0.90$).

Thirty-two (50.8%) residents at pre-intervention and 21 (37.5%) at post-intervention had trouble with breathing. Of these there was a non-significant increase pre- to post-intervention in residents receiving the right amount of health in dealing with their breathing (80.6 v 90.0%, $p=0.46$).

Thirty (48.4%) and 26 (46.4%) of respondents at pre- and post-intervention, respectively, felt the resident had feelings of anxiety or sadness. Of those reporting these symptoms, there was non-significant increase with respect to the resident receiving the right amount of help in dealing with these feelings (68.0 v 75.0%, $\chi^2=0.29$, $p=0.59$).

There was a borderline significant increase pre- to post-intervention in the proportion of respondents indicating a problem with doctors or nurses not knowing enough about the resident's medical history to provide the best possible care (13.4 v 26.3%, $\chi^2=3.68$, $p=0.06$).

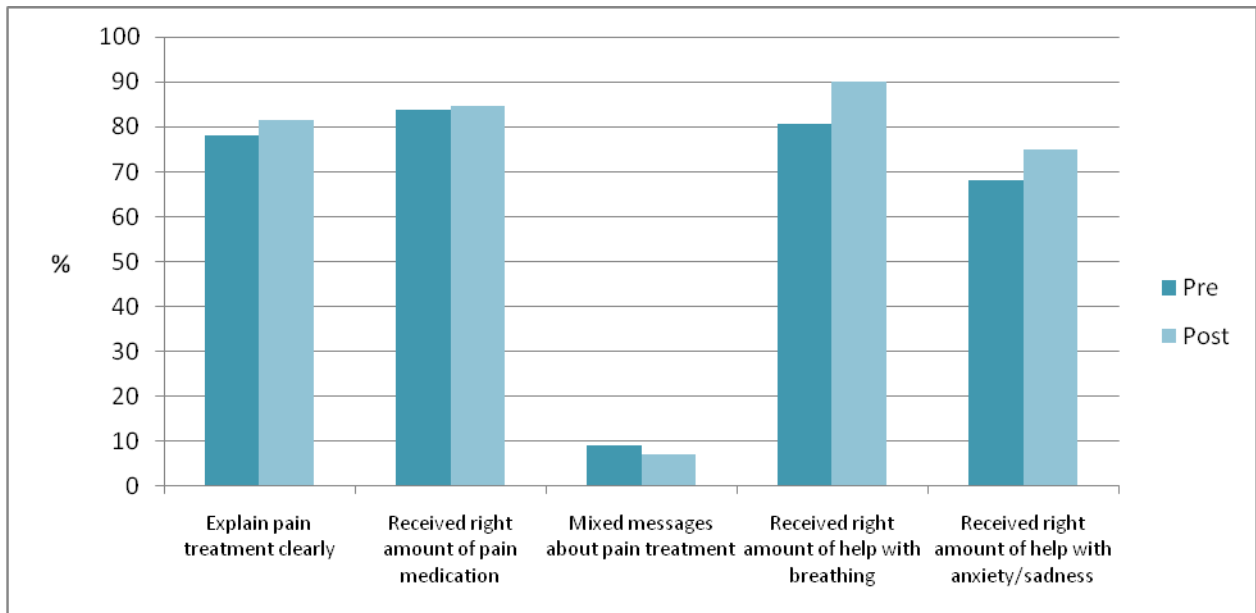


Figure 14: Family member interview outcomes for symptom management

RACF involved family

There was no change pre- to post-intervention in:

- Decisions being made without enough input from the resident or family (14.5 v 17.5%, $\chi^2=0.24$, $p=0.62$)
- Family members always being kept informed about the resident's condition (59.8 v 64.9%, $\chi^2=0.44$, $p=0.80$).

Care activities

There were no significant differences pre- to post-intervention in:

- Personal care needs – such as bathing, dressing, and changing bedding – always being taken care of as well as they should have been (68.3 v 66.7%, $\chi^2=0.04$, $p=0.84$)
- Proportion indicating they were never concerned about resident's personal care needs being met when they were not there (65.1 v 70.2%, $\chi^2=3.47$, $p=0.18$)
- Proportion indicating there was enough help to meet personal care needs, like bathing, dressing, feeding and going to the bathroom (84.5 v 87.5%, $\chi^2=0.24$, $p=0.81$)
- Proportion indicating there was enough help with medications and getting dressing changed (96.4 v 96.4%, $p=1.00$)

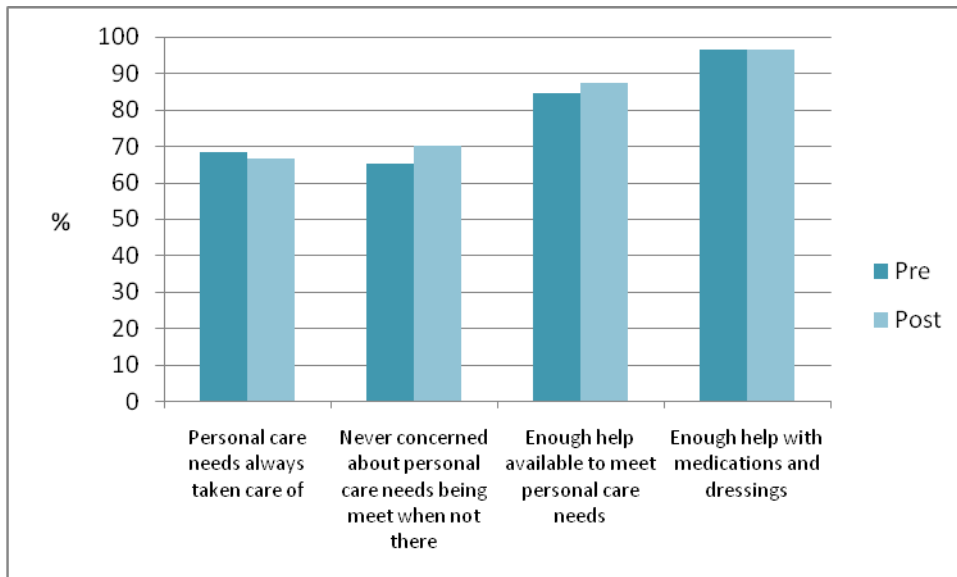


Figure 15: Family member interview outcomes for care activities

Respect and kindness

There was no significant change in residents:

- Always being treated with respect by those taking care of him/her (83.1 v 77.2%, $\chi^2=0.77$, $p=0.38$)
- Always being treated with kindness with those taking care of them (79.5 v 82.5%, $\chi^2=0.19$, $p=0.67$)

Information in the terminal phase

For the next-of-kin of deceased residents, there was a non-significant increase pre- to post-intervention in the receipt of information about:

- what to expect while the resident was dying (55.4 v 69.0%, $\chi^2=1.63$, $p=0.20$)
- what to do at the time of residents' death (41.5 v 50.0%, $\chi^2=0.62$, $p=0.43$)
- medicines that would be used to manage his/her pain, shortness of breath, or other symptoms (65.5 v 69.0%, $\chi^2=0.12$, $p=0.73$)

There was a significant decrease in the proportion of next-of-kin who would have wanted some/more information about what to expect when the resident was dying (33.7 v 13.8%, $\chi^2=4.19$, $p<0.05$). And non-significant decreases in those who wanted some/more information on:

- what to do at the time of resident's death (29.3 v 17.2%, $\chi^2=1.61$, $p=0.21$)
- medicines that would be used (27.4 v 13.8, $\chi^2=2.19$, $p=0.14$)

There were non-significant increases pre- to post-intervention in the proportion of next-of-kin who reported they felt "very confident" they:

- knew what to expect while the resident was dying (50.0 v 58.6%, $\chi^2=2.56$, $p=0.28$)
- knew what do at the time of death (56.1 v 69.0%, $\chi^2=1.68$, $p=0.43$)
- understood about the medicines that would be used (45.8 v 62.1, $\chi^2=2.44$, $p=0.30$)

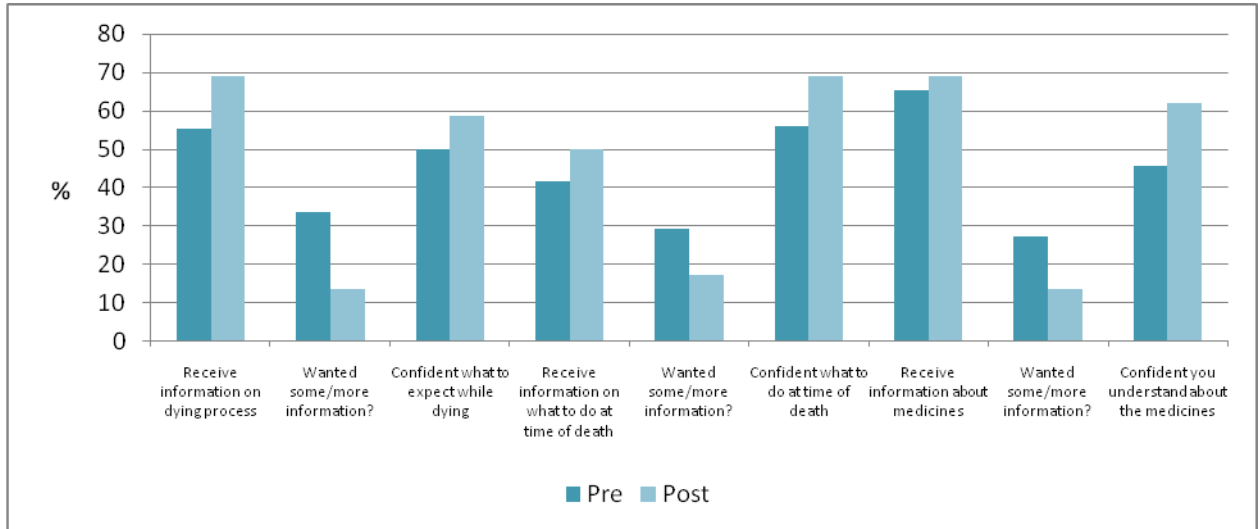


Figure 16: Family member interview outcomes for information on the terminal phase

Support

There were non-significant decreases pre- to post-intervention in:

- Someone talking to the next-of-kin about their religious or spiritual beliefs (35.7 v 24.6%, $\chi^2=1.97$, $p=0.16$)
- Respondents receiving the right amount of support from the doctors and nurses to deal with their feelings about the residents' death (85.5 v 82.5%, $\chi^2=0.24$, $p=0.62$)

There was a borderline significant increase pre- to post-intervention in the proportion of respondents indicating that a doctor or nurse had talked to them about how they might feel after the resident's death (24.7 v 43.3%, $\chi^2= 3.63$, $p= 0.06$). And there was a non-significant increase in doctors or nurses suggesting someone family could turn to for help if they were feeling stressed (29.6 v 36.8%, $\chi^2=0.79$, $p=0.37$).

All respondents receiving spiritual support stated it was done in a sensitive manner, and all but one pre-intervention respondent stated they received as much contact of this kind as they wanted. Further, all but one pre-intervention respondent, indicated that discussions about how they might feel after the resident's death were conducted in a sensitive manner. Of those not having this discussion, 33.3% and 25.0% at pre- and post-intervention respectively indicated they would have liked this issue brought up.

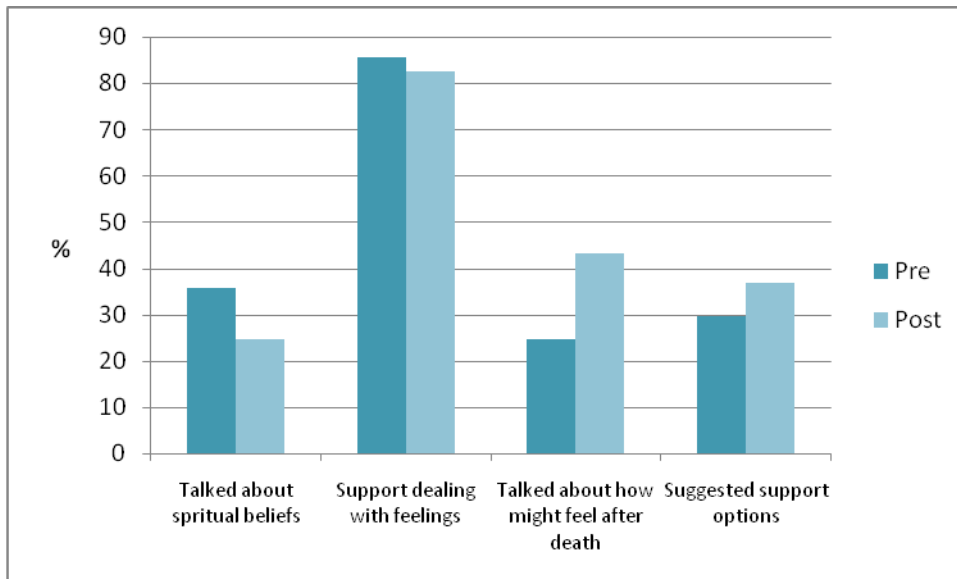


Figure 17: Family member interview outcomes for support

Ratings

Family were asked to rate the facilities performance on various factors on a 11-point (0-10) Likert scale with 0 meaning the worst care possible and 10 meaning the best care possible. Table 6 indicates there were no significant pre- to post-intervention differences.

Table 6: Comparison of pre- and post-intervention ratings

Item	Pre			Post			Mann-Whitney	
	N	Mean	Median	N	Mean	Median	z	p
Communicated with resident/family about the illness and likely outcomes of care	82	7.54	8	56	7.88	9	-.81	0.42
Provided care that respected wishes	81	8.90	9	56	8.68	9	-.62	0.53
Made sure symptoms were controlled to acceptable degree	81	8.48	9	56	8.78	9	-1.08	0.28
Made sure resident died with dignity	80	9.09	10	29	8.86	10	-.33	0.74
Provided emotional support for family and friends	83	7.51	8	56	8.17	9	-1.68	0.09
Overall care received	84	8.52	9	57	8.70	9	-0.94	0.35

3.3.2.2 Issues raised by families at palliative care case conferences

Twenty-nine next of kin completed the family questionnaire prior to the palliative care case conference (see Appendix 11 for a copy of the questionnaire).

The main concerns brought up by respondents included:

- Pain and comfort (n=10): “is she comfortable and pain free?”; “mother’s care and comfort are the main issues”
- Current physical concerns (n=9): “Pain, bowel, eating, drinking, dehydration”; “confusion”

- Social isolation (ability to communicate, awareness) (n=5): “inability to converse - voice fades away”; “I am distressed not being able to know what awareness he has of what is happening to him.”
- End of life wishes e.g., resuscitation, last rites (n=4): “That no resuscitation measures be undertaken in the event of a cardiac or respiratory arrest.”
- Hygiene (n=4): “His incontinent pads should be checked regularly... his fingernails are kept clean ... his teeth are cleaned regularly and mouth rinsed afterwards.”
- Emotional health e.g., depression and anxiety (n=3): “her crying and possible depressive state of mind”
- Quality of life e.g., stimulation (n=3): “I hope she will be able to have some stimulation for as long as possible and not be left in bed until necessary as this agitates her”
- Decreased appetite (n=2)
- Communication between family and facility e.g., asking questions (n=1)
- Treatment of existing medical conditions (n=1)
- Dignity (n=1)

The respondents wanted to ask about the following issues at the case conference:

- Residents’ illness/ physical and medical needs (n=11): “How serious is her condition?”; “Why does she sleep so much?”; “How ill is my mother as I know she goes through a lot of pain”
- What does the facility do to help the relative? (n=8): “What techniques offered for soothing, eg touch, aromatherapy, music?”; “Are enough staff available for optimal care?”; “Will the staff’s English be adequate?”
- What can the family do/ what is the families’ role? (n=6): “What is the procedure during my father’s last days ... This also includes funeral arrangements and anything I need to do personally about it”; “What can we do to best help her? (emotionally/physically)”
- Hospital versus facility in terminal phase (n=1)
- Difference between palliative care usual care (n=1)
- Funeral and other arrangements for death (n=1)
- Grief management/ counselling (n=1)
- Pastoral care (n=1)
- Procedure in final days (n=1)
- Stages in decline to terminal phase (n=1)

3.3.2.3 Family feedback on the palliative care case conferences

Interviews were conducted with fifty-eight (58) relatives of residents who had participated in case conferences (see Appendix 12 for a copy of the questionnaire). When asked what they found most helpful about the palliative care case conference, responses included:

- Found out more about relative’s condition/what to expect (n=16, 28%)
- Everyone ‘on the same page’ - wishes/issues discussed and clarified (n=13, 22%)
- Understanding through discussion/questions answered/ open discussions/ one-on-one with staff (n=12, 21%)
- Confidence in the facility/staff/process (n=10, 17%)
- Family finding out how they can help/contribute (n=2, 3%)
- Limited benefit (n=1, 2%)

The majority of respondents (n=48, 83%) stated there was nothing facilities could do to improve the palliative care case conference process: “nothing, it was brilliant”; “I’m happy with the way things went”. Suggested improvements included:

- Lack of support before the case conference - overwhelmed/ didn't know what to expect (n=4, 7%): "having an agenda up front so we were sure about what was being covered."
- Reassurance that resident will be cared for/ support (n=4, 7%)
- Family attendance or other health professionals including GP (n=2, 3%)

Sixty-two percent (36/54) of relatives stated that they had raised issues and concerns at the case conference and 85% of this group felt their issues were acted upon by the facility. Over 90% of family members (50/55, 90.9%) felt their views/wishes were respected during the case conference. Nearly 90% of next-of-kin (49/55, 89.1%) felt they had received enough information about their family member's care, with just over 10% (6/55, 10.9%) reporting they received less than was needed. All respondents (55/55) would recommend RACFs continue conducting palliative care case conferences.

3.3.3 Impact on staff

3.3.3.1 Staff survey

Appendix 13 outlines pre- and post-intervention results for the Palliative Care Providers Evaluation Tool 2.1, for nursing and care staff. Across the nine facilities, the survey was completed by 102 nurses and 210 care staff at pre-intervention, and 76 nurses and 166 care staff at post-intervention. Response rates for individual facilities ranged from 28.0 to 65.4% and 31.9 to 56.2% at pre- and post-intervention, respectively.

Views on palliative care

Nurses exhibited a 10% or greater increase pre- to post-intervention in the number of respondents reporting they were "confident to perform independently" the following tasks:

- Supporting the resident or family member when they become upset (52 v 68%)
- Discussing different environmental options (e.g., hospital, aged care facility, hospice) (28 v 41%)
- Reacting to reports of pain from the resident (53 v 69%)
- Reacting to and coping with terminal dyspnoea (47 v 57%)
- Reacting to and coping with nausea/vomiting (59 v 72%)
- Reacting to and coping with reports of constipation (61 v 71%)
- Reacting to and coping with limited resident decision-making capacity (38 v 54%)

Viewing post-intervention outcomes, nurses were most confident (confident to perform independently) with:

- Reacting to and coping with nausea/ vomiting (72%)
- Reacting to and coping with reports of constipation (71%)
- Reacting to reports of pain from the resident (69%)
- Supporting the resident or family member when they became upset (68%)

Care staff did not exhibit a 10% or greater change on any items in this sub-section.

Viewing post-intervention outcomes, care staff were most confident (confident to perform independently) with:

- Reacting to and coping with nausea/ vomiting (41%)
- Reacting to and coping with reports of constipation (37%)
- Supporting the resident or family member when they become upset (35%)
- Reacting to reports of pain from the resident (34%)

Views about death and dying

Nurses displayed a 10% or greater increase pre- to post-intervention in the number of respondents strongly disagreeing with the statement “feeding tubes should be used to prevent starvation at the end of life” (55 v 65%). There was a 10% or greater decrease pre- to post-intervention in the number of respondents unsure about the statement “the use of strong medication can cause the person to stop breathing” (20 v 8%).

Viewing post-intervention results, nurses felt most strongly about the following statements with 65% or more strongly disagreeing with:

- Aged care facilities are not good places to die (67%)
- When a resident dies I feel that something went wrong (65%)
- Feeding tubes should be used to prevent starvation at the end of life (65%)

Care staff displayed a 10% or greater increase in the number of care staff “disagreeing” with the statement “feeding tubes should be used to prevent starvation at the end of life” (27 v 39%).

Viewing post-intervention results, care staff felt most strongly about the following statement with 47% strongly disagreeing with the statement:

- I am not comfortable caring for a dying resident

Attitudes towards Palliative Care

From pre- to post-intervention, nurses exhibited a 10% or greater decrease in the number of respondents who neither agreed or disagreed with:

- Palliative care should be the standard medical treatment for residents who are suffering from a terminal illness (16 v 3%)
- Addiction to oral morphine is not a serious issue given that terminally ill residents have a short time to live (15 v 5%)

There was also a 10% or greater decrease in the number of respondents who disagreed with the statement “the most appropriate person to make end-of-life decisions is the resident’s doctor” (50 v 37%).

Nurses felt most strongly about the statements relating to pain, with approximately 70% “strongly agreeing” with:

- Pain medication should be given as needed to terminally ill residents (70%)
- Residents should be maintained in a pain-free state (68%)

And approximately 70% “strongly disagreeing” with:

- A resident should experience discomfort prior to receiving the next dose of pain medications (68%)

Care staff displayed a 10% or greater increase pre- to post-intervention in the proportion of respondents who agreed with the following statements (with the “strongly agree” response decreasing):

- Spiritual care should include counselling the terminally ill resident (41 v 52%)
- Residents have the right to determine their own degree of psychosocial intervention (41 v 57%)

There was a 10% or greater decrease pre- to post-intervention in the proportion of respondents who strongly agreed with the following statement (with the “agree” response increasing):

- Pain medication should be given as needed to terminally ill residents (55 v 44%)

Viewing post-intervention results, care staff felt most strongly about the following, “agreeing strongly” with:

- Residents should be maintained in a pain-free state (45%)
- Pain medication should be given as needed to terminally ill residents (44%)
- Residents should have the right to determine their own degree of medical intervention (37%)

And “disagreeing strongly” with:

- A resident should experience discomfort prior to receiving the next dose of pain medications (36%)

Importance of issues

For nurses, when asked to rate the importance of issues in terms of the problems they create in caring for a dying resident, there was a 7% increase in rating *Communication with other palliative staff* as “very important”. The following factors decreased in importance from pre- to post-intervention:

- Legal concerns (51.5 v 41.9%)
- Ability to meet spiritual needs (67.0 v 60.0%)
- Uncertainty about what is the best care (38.1 v 32.8%)

For care staff, the following factors decreased in importance from pre- to post-intervention:

- Control of pain (87.8 v 82.6%)
- Communication with other palliative care staff (73.5 v 66.5%)
- Communication with (other) doctor/s (60.9 v 55.0%)

3.3.4 Impact on the residential aged care facilities

3.3.4.1 Feedback from the DON

9/9 facility representatives completed the *Palliative Care Service Self-Assessment (Evaluation Tool 3.1)* at pre-intervention and 8/9 at post-intervention. There was little difference in what was indicated as “present” pre- to post-intervention (see Appendix 14).

3.3.4.2 Feedback from Project Liaisons and Link Nurses

Twenty-two (22) project liaisons and link nurses completed a CEBPARAC feedback questionnaire which included structured and open questions.

Views on CEBPARAC

Asked what they liked about the project, the most common response (n=7) related to clarifying or defining the palliative approach: “it defined how our facility acknowledges and practices nursing for residents in a palliative stage”; “it helped consolidate the palliative approach”. Other responses related to:

- gaining knowledge or resources (n=5): “gaining knowledge and reference material”; “it was very informative - covered a wide range of issues”
- appreciation of key processes including palliative care case conferences and the RAC EoLCP (n=5)
- project support (n=5): “support from research team”
- increased communication between stakeholders (n=4)
- engagement and empowerment (n=2)
- structure and ease (n=1)

Respondents also commented on what didn't work so well or what could be improved.

Reponses included:

- Difficulty engaging certain stakeholders (e.g., family, GPs, staff) (n=4): "getting staff to implement end of life pathway – initially unfamiliar etc"
- Implementation problems (n=4): "implementing the EoLCP – residents died before being commenced"; "it could be made clearer on how to commence the pathway"
- Link nurse availability (n=4): "change of link nurses due to people changing roles"; "if the key person or link nurse was not on site then the project was not commenced. Improvement - to make several people key people, and spread out over different shifts to cover all days and times"
- More time to complete tools/ gain confidence with tools (n=3)
- Making staff aware that pathway has commenced and needs to be utilised (n=2)
- Needs to be more specific/ brief (n=2)

Link nurses

Almost all respondents (21, 95%) agreed it was necessary for a RACF to have a "link nurse" or champion to set up a palliative approach. Reasoning for this included:

- Central person to facilitate and maintain process (n=14): "need a driver, someone to keep staff committed to ongoing case conferences"; "there has to be a "standard bearer" - single person for job to lead it"
- Someone to engage stakeholders (n=4)
- Someone to accept responsibility (n=1)

Evidence-based tools

Evidence-based tools, like the Cornell Scale for Depression and the Abbey Pain Scale, were already commonly used in the facilities (see Table 7). The most commonly trialled tools during the course of the project included the RAC EoLCP and the M-RVBPI. Project liaisons and link nurses indicated that they were least likely to have trialled the CAM or Modified Bereavement Risk Index.

Table 7: Use of evidence-based tools by project liaisons/link nurses

Tool	Already in use in our facility (%)	Tried during the CEBPARAC project (%)	Did not try (%)
Abbey Pain Scale	77	5	5
Modified Resident's Verbal Brief Pain Inventory (M-RVBPI)	27	50	5
Edinburgh Feeding Evaluation in Dementia (EdFED)	32	41	9
Oral Health Assessment Tool	36	27	9
Confusion Assessment Method (CAM)	5	18	50
Cornell Scale for Depression	82	5	5
Modified Bereavement Risk Index	14	32	36
Residential Aged Care End of Life Care Pathway	18	68	5

The primary reasons that tools were not used included:

- Felt current tools were suitable for their needs (n=5): "would require doubling up"
- Not relevant to residents' needs (n=5): "didn't use CAM as no need for selected residents"
- Staff resistant to use (n=1)
- Time (n=1)

CEBPARAC resources

Respondents indicated they used the following CEBPARAC resources in their facilities:

- Link nurse training manual (91%)
- Implementation folder (91%)
- “Understanding the dying process” brochure (86%)
- Assessment and management flowcharts (73%)
- “Now what? Understanding grief” brochure (73%)
- Self-directed learning package (64%)
- “All on the same page” DVD (50%)

Education

The project liaisons and link nurses were asked to rate various educational options in terms of usefulness. Results, in order of usefulness, included:

- Link nurse training day (20/20, 100% ranked “very useful”)
- Facility training sessions (19/19, 100% ranked “very useful”)
- Link nurse training manual (19/21, 90% ranked “very useful”; 2/21, 10% ranked “moderately useful”)
- “All on the same page” DVD (15/18, 83% ranked “very useful”; 3/18, 17% ranked “moderately useful”)
- Monthly reviews (12/16, 75% ranked “very useful”, 4/16, 25% ranked “moderately useful”)
- Self-directed learning package (14/20, 70% ranked “very useful”; 5/20, 25% ranked “moderately useful”; 1/20, 5% ranked “not at all useful”)
- Link nurse e-newsletter (9/16, 56% ranked “very useful”, 6/16, 38% ranked “moderately useful” and 1/16, 6% ranked “not at all useful”)

Four to five of the respondents felt they could not comment on the link nurse e-newsletter or the monthly reviews because they had either not accessed or not been involved.

Respondents felt the following strategies were most effective in educating nurses: facility presentations (n=13, 59%); Link Nurse training days (outside the facility) (n=6, 27%); and having an expert in the facility (n=1, 5%). They thought the following strategies were useful for educating care staff: regular facility presentations/ reviews (n=12, 55%); job enrichment (e.g., attending case conferences (n=5, 23%); DVDs/ self directed learning packages (n=4, 18%); mentoring (n=2, 9%); and mini-sessions fitted into the work-day (e.g., staff meetings) (n=2, 9%).

Palliative care case conferences

Eighty-two percent of respondents stated that they had participated in or attended a palliative care case conference during the CEBPARAC project. The following factors were identified as the most useful aspects of a palliative care case conference:

- Chance for family to express concerns/ feelings (n=6, 27%)
- Involvement of stakeholders (n=6, 27%)
- Communication between stakeholders (n=4, 18%)
- Staff able to support family (n=2, 9%)

Suggestions for improvements to palliative care case conferences included:

- A time limit (n=4, 18%)
- Structure (n=3, 14%)
- Encouraging GPs/other stakeholders to attend (n=2, 9%)
-

Twenty-one out of the 22 respondents stated they would like to continue with palliative care case conferences in their facility and one respondent was unsure. In terms of confidence in leading/ facilitating a palliative care case conference, 9 (41%) felt “very confident”, 10 (45%) felt “moderately confident” and 1(5%) indicated they were “not at all confident”.

RAC EoLCP

All but one respondent (95%) stated they had used the RAC EoLCP and 95% stated they would like to keep using the RAC EoLCP with their residents. When asked what they liked about the tool 14 (64%) respondents stated that the RAC EoLCP was easy to use and seven (32%) identified its structure and direction. Four respondents identified possible improvements for the tool, relating to its implementation: “training staff on how to implement...”; “it could be made clearer as to how to commence on the pathway.”

Staff roles

The role of the nurse in palliative care is perceived as one of leadership, advocating for the patient, and organising/engaging stakeholders in their collaborative effort. Respondents identified the following:

- Advocates/ maintains focus on resident comfort (n=6, 27%)
- Assessment of residents and planning each resident’s palliative care (n=3, 14%)
- Source of knowledge and support (n=3, 14%)
- Point of contact for family (n=2, 9%)
- Build confidence in stakeholders (n=1, 5%)

The AIN is perceived as providing the “hands on” care and comfort. Importantly, a number of respondents noted that they are “the eyes and ears” of RNs, providing important feedback regarding residents requiring palliative care. The following was identified:

- Basic care and comfort; “hands on” in implementing the plan (n=10, 45%)
- Upholding the palliative approach – caring/ dignity at all times (n=6, 27%)
- Providing feedback to nurses (n=4, 18%)

Barriers and facilitators

The link nurses and project liaisons identified the following barriers and facilitators to maintaining a palliative approach in their facility.

Barriers:

- Resistance from staff; staff attitudes (n=8; 36%)
- Resources – time/cost (n=4, 18%)
- Understanding/ knowledge (n=4, 18%)
- Lack of processes/ structure to make it work (n=2, 9%)

Facilitators:

- Staff interest/ support/ involvement (n=12, 55%)
- Link nurses (n=5, 23%)
- Embedded structure (n=1, 5%)

3.3.4.3 Feedback from GPs

A total of 14 general practitioners (GPs) were engaged in palliative care case conferences as part of the project. Of these, 11 agreed to a face-to-face interview. The interviews focused on their views on providing a palliative approach in residential care and in particular their experience with attending a palliative care case conference and where applicable the use of the RAC EoLCP.

The role of the GP in relation to palliative care of a resident

Participants identified that their role in palliative care included medication management, activities related to diagnosis, prognosis and symptom relief. Nurses work in relation to palliative care concerned the day to day hands on work.

Purpose and usefulness of the palliative care case conference

The primary purpose and goals of the palliative care case conference were varied and included:

- Education opportunities for the family
- Education opportunity for the GP (referring to learning from the specialist palliative care nurse if in attendance)
- Discussion regarding place of care options and clinical management
- Opportunity to discuss palliative care as an early option rather than last few days of life
- Opportunity to provide comfort for family and support
- Prioritise care and clarify roles of the team members
- Discussion of issues concerning QOL and ADLs
- Opportunity to complete the good palliative care form
- Opportunity for different values to emerge

Who should attend a palliative care case conference

There was general agreement that attendees should include:

- GP
- Family
- Nursing staff
- Specialist palliative care nurses if required or available
- Other specialists – geriatrics
- Pharmacists

There was some discussion about the appropriateness of the resident and that this should be on a case by case basis. Concerns included the resident with dementia or depression.

Barriers to attending a PCC

While all GPs interviewed had attended at least one case conference barriers for GPs to attend were identified. These included:

- Time – however comments included that time spent at a palliative care case conference can save time in the long run
- Medicare reimbursements – seen as inadequate by some but not by others
- Claiming for reimbursement is not always a priority
- Teleconferences were not seen as desirable and were not necessary as most were located within a geographical proximity that allowed face to face visits
- No appropriate physical space
- If palliative care case conference exceeded one hour
- If the palliative care case conference only addressed emotional or conflict issues and not clinical care concerns
- If a GP was new or inexperienced in palliative care (attendance by a specialist palliative care nurse in these instances was highly valued)
- Residents or families from CALD backgrounds if language was a barrier

Facilitators to attending a palliative care case conference

A number of strategies were identified that would facilitate the use of palliative care case conferences in residential care. These included:

- Time – if time poor specific issues requiring the GP could be addressed at the beginning of the conference
- Having the palliative care case conference organised in advance by staff from the facility

- Having a clear structure and use of a proforma (as in the case of the CEBPARAC project)
- Having a facilitator that was skilled and this could be a specialist palliative care nurses, registered nurses or enrolled nurse

End of Life care pathways

No GPs had prior knowledge of end of life care pathways included the RAC EoLCP used in the project. One GP commented that he thought it was more of a nursing tool. Of the GPs interviewed six had residents who had been commenced on the RAC EoLCP. Other comments regarding the pathway included that it focuses the nurses, assists with communication with agency staff and is useful for GPs.

3.4 Dissemination

The project was featured in several industry magazines, including Palliative Care Australia e-bulletin and Blue Print (Blue Care).

Media releases were circulated during Palliative Care Week to the following industry publications radio stations, and local newspapers: Australian Ageing, Agenda magazine, Australian Ageing, Agenda online, Insight magazine, Insight online, Nursing Review magazine, Aged Care Housing Weekly, Gold Coast Bulletin, Gold Coast Sun, Gold Coast Mail, Tweed Daily, The Border Mail, ABC Gold & Tweed Coasts, Sea FM Gold Coast, Westside News (Quest).

Project pages were placed on the CareSearch website (www.caresearch.com.au) and the University of Queensland website.

Project brochures and newsletters were circulated to the facilities, GPs, recruited families and reference group members.

Conference presentations included:

- Parker, D (2009). Implementation of a comprehensive evidence-based palliative approach in residential aged care. *Centre for Palliative Care Research and Education Annual Conference*. Brisbane: 5 June.
- Parker, D. (2009). Implementing an evidence-based model of palliative care in residential aged care. *Joanna Briggs Institute International Convention*, Adelaide, 20-21 November.
- Parker, D., Greeve, K., Hegney, D., Hughes, K., Jenkin, P., Reymond, E., Walker, H. (2009). Implementation of a comprehensive evidence-based palliative approach in residential aged care. *42nd National Conference of the Australian Association of Gerontology*, Canberra, 25-27 November.
- Parker, D. (2010). Palliative care case conferences and end of life care pathways in residential aged care. *Royal Brisbane and Women's Hospital in the Nursing Home Aged Care Conference*. 7th-9th July, Brisbane.
- Parker, D., Greeve, K., Hughes, K., Jenkin, P., Reymond, L., Tuckett, A. & Walker, H. (2010). Palliative care in residential aged care. *Palliative Care Nurses Australia Conference – Excellence and Innovation*. 27th-28th August, Brisbane
- Greeve, K. (presenter), Parker, D., Hughes, K., Jenkin, P., Reymond, L., Tuckett, A., Walker, H. (2010). Implementing an evidence-based model of palliative care in residential aged care. *Western Australian Palliative Care Conference - "At the Coalface"*. 28th May, Perth.

3.5 Sustainability

Note the report - Encouraging Best Practice in Residential Aged Care: Palliative Care Workshop Report from the Melbourne combined Palliative Care Projects provides information regarding sustainability. These findings are not repeated in this report.

a. Implementation across aged care sector

The time and labour intensive aspects of this model were completed within the project timeframe and budget. These included the development of the generic templates for policies, procedures, documentation, production of the case conferencing DVD and self directed learning packages for nurses and careworkers. All of these can be made available to the aged care sector supported by a range of training materials and resources which are already available but not routinely used in RACFs. The implementation across all RACFs in Australia will be possible by the production of the Palliative Approach (PA) Toolkit which outlines a step by step approach for each RACF to implement the model with the resources provided. The PA Toolkit could be made available on the Care search website. The documentation provided in the Toolkit is flexible enough for each RACF to modify according to size and local variation.

The PA Toolkit maps a palliative approach to current Aged Care and Palliative Care Standards and in particular Standard 2.9 Palliative Care and Standard 2.8 Pain Management. The palliative care case conference which is a key process in the PA Toolkit assists in RACFs assessing residents for applying for funding using ACFI. This will provide sustainability for the RACF by claiming for the time required to meet the resident needs for palliative care as reimbursed using ACFI. The RACPAN network is an ongoing network that can assist in providing an avenue for RACF staff to discuss issues and concerns regarding implementation.

b. Sustainability of homes participating as part of the project

This model was designed to build capacity within the RACF using the existing funding available to RACFs. The model developed was integrated into existing service delivery within the RACF, no new staff members were required for this model to be used. The involvement of the staff within each RACF in the implementation provided the transition required to embed the model within usual practice.

For each RACF participation in the project provided staff with the necessary policies, procedures and documentation to meet the Accreditation Standards for Palliative Care and Pain Management and claim for the necessary hours required to care for the palliative care needs of their residents. In this way the model has become self sustaining using existing Commonwealth resources. A key feature of the model of care is the use of case conferencing which can be reimbursed by Medicare and is therefore financial sustainable for both the GP and the RACF.

Each RACF has at least one trained link nurse (most have multiple) and with the self directed learning packages for nurses and care staff can undertake further in-house training to develop other link nurses as well as up skill new staff and provider refresher opportunities for existing staff. This aspect is particularly important within a sector with an aged and fluid workforce.

Two DVDs – the existing resource from Palliative Care Australia – Suiting the Needs and the DVD produced for the project – ‘On the same page’ Palliative Care Case Conferencing in Residential Aged Care form the basis of the self directed learning packages. They can also outside of this function be viewed by all new staff employed at the facility and can also be used to provide clinical updates for existing staff.

All project RACFs will have access to the PA Toolkit as an outcome of the project. It is also envisaged that personal relationships established between consortium members and the project team will continue and further opportunities for practice development may be possible.

4 Discussion and conclusions

The aim of this project was to implement and evaluate a comprehensive evidence based palliative approach in residential aged care. This aim was achieved by completion of all the original project objectives. That is:

1. The translation of existing evidence based guidelines (palliative care and pain management) into policy and practice (including documentation).
2. Provision of education to all nursing and care staff at all levels working in the RACFs using existing training materials (where applicable).
3. Development of a palliative care case conferencing learning resource (DVD) for residents and family members, nursing staff and GPs.
4. Training and support of link nurses in each RACF.
5. Implementation of the BSPCC Residential Aged Care End-of-life Care Pathway (RAC EoLCP) for residents requiring terminal care.
6. Developing from existing training modules a self-directed learning module for Link nurses.
7. Promoting the use of existing GP on-line training modules to support GPs in providing a palliative approach to residents in their care.

Factors contributing to the success of the project which assisted meeting the project objectives included:

- Key stakeholder involvement throughout the project which included Specialist Palliative Care Services, General Practitioners, residents, families, project liaisons (management level), link nurses (clinical level) and all levels of clinical staff particularly care workers.
- Translation of guidelines into resources and processes that resonated with clinical staff. This included the focus on three key processes of care – advance care planning, palliative care case conferences and the use of an end of life care pathway as well as symptoms commonly encountered in palliative care.
- Linkage of key processes and clinical care with existing standards and funding mechanisms. In particular this included, Aged Care Accreditation Standards, Palliative Care Australia Standards, the Aged Care Funding Instrument and Medicare items for GP reimbursement.
- Regular engagement both pre-, during and post-implementation by the project staff with General Practitioners, Specialist Palliative Care Services, project liaisons, link nurses and facility staff to embed practices within the local context.

Factors that were challenging but that did not prevent the project from meeting its objectives

- Limited time available for clinical care staff to attend dedicated education sessions and ongoing learning opportunities such as monthly reviews.
- Differing management styles some of which more actively promoted the attendance of staff at education and up-take of evidence based practice.
- Periods of minimal response from facilities due to higher priorities e.g., accreditation.
- Changes in staffing at some aged care facilities, staff going on extended leave and part-time staff can impact on timelines.

- Link nurses and project liaisons vary in how actively they champion the CEBPARAC project in their facility. Some are very proactive: they familiarise themselves with the materials and actively engage residents, families and other staff to be involved.
- Mixed enthusiasm for monthly reviews because these do not correspond to the facilities usual three/six month review process.
- Some difficulty encouraging project liaisons/ link nurses to encourage/ take staff off the floor for palliative care case conferences and monthly reviews.

Lessons learnt during the course of the project that might be useful for someone else

Changing practice is challenging and complex and in particular changing policy or documents to reflect a new practice. There is some indication that recommended evidence-based practice may not always correspond to current practices. This is predominantly concerning the use of valid and reliable evidence based assessment tools. For example not all facilities used the recommended pain assessment tools despite these being available since 2005. However, there was a willingness to try new assessment tools once staff were aware of their existence and importance in improving practice. In the context of a specific project however, these tools are not standardised as part of routine documentation and for those facilities using e-records they do not exist on the system. Time commitment to embed new assessment tools or forms into the system is not possible without proven value. In some facilities the assessment tools or forms are now being processed to meet the standardised requirements of the facility. However, during a project it is the case that double documentation is required.

The sustainability of the project within participating facilities

The time and labour intensive aspects of developing an evidence based palliative approach have been completed as part of this project. The final product, the Palliative Approach Toolkit, provides the templates and resources required to implement a palliative approach and staff have been upskilled in the use of the model of care. A challenge for any change in practice to be sustained is staff turnover, workload and currency of product.

A range of strategies for sustainability are embedded in the final product. These include:

- The model developed was integrated into existing service delivery within the RACF, no new staff members were required for this model to be used.
- Educational resources such as self directed learning packages linked to high quality DVDs for all staff levels. These learning packages can be completed by new staff but can also be used by existing staff. The introduction and advanced package for registered and enrolled nurses attracts continuing professional development points.
- The key processes that are the feature of the model of care are linked to existing funding mechanisms such as ACFI and Medicare Items for General Practitioners.
- Where possible the caresearch website is referred to for information that is likely to change within the space of the next five years. This is specifically regarding advance care planning legislation. The existing Toolkit should however be reviewed and updated every five years.

Conclusions

This project has been successful in implementing a comprehensive evidence based palliative approach in residential aged care. It has met the program objectives of EBPRAC by:

1. **Improvements in clinical care** - Evaluation data provides evidence of improvements in the clinical care of residents as a result of the model of care. In particular this is demonstrated by significant improvements in symptom management,

- communication, advance care planning, bereavement care, referrals to specialist services (palliative care, pain management) and care in the final days of life
2. **Opportunities for aged care clinicians to develop and enhance their knowledge and skills** – Evaluation data provides evidence that aged care staff of varying levels have had the opportunity to enhance their knowledge and skills in providing a palliative approach. This has been achieved using the educational resources developed for the project as well as existing resources that had not been accessed. In addition, role modelling of clinical care from specialist palliative care nurses has significantly enhanced skills in how to organise and facilitate a palliative care case conference and implement an end of life care pathway.
 3. **Support staff to access and use the best available evidence in everyday practice** – The development of the Toolkit has provided the opportunity for aged care staff to access and use the best available evidence in providing a palliative approach. Promotion of the caresearch website as a host for project materials and integration of this in staff training will ensure ongoing awareness of new evidence as it is developed.
 4. **Wide dissemination of proven best practice in clinical care** –Project dissemination of the model of care has occurred at national and international forums.
 5. **Development of national clinical or education resources that support evidence-based practice** – The PA Toolkit contains high quality evidence based resources that will assist all aged care facilities in providing a palliative approach. Designed using the best available evidence they are user friendly and generalisable to facilities regardless of size or location.
 6. **Build consumer confidence in aged care facilities** – Evaluation data provides evidence that the model of care increased satisfaction from carers in regard to communication particularly with the General Practitioner via attendance at a palliative care case conference. Explaining the palliative approach and the dying process appeared to reduce family uncertainty and anxiety. Promotion of the project via resident committees, brochures and newsletters has also provided opportunity to build consumer confidence in how aged care facilities support dying residents and their families.

5 Recommendations

- Implementation of evidence based practice requires commitment from all levels of staff and support from management.
- Dedicated education sessions for all levels of staff will assist with implementing evidence based practice.
- Education on any evidence based practice must precede implementation and regular follow up education sessions for new and existing staff will assist with embedding practice change.
- Identification of link nurses (champions) to coordinate and drive practice will assist in embedding practice change. Multiple link nurses that have this role clearly designated increases the chance of success.
- Where required seek the assistance of experts external to the organisation – these may be clinical experts or those knowledgeable in evidence based practice.
- Reinforce that evidence based practice will assist the organisation in meeting Standards and in some instances may enhance funding options.
- The final product designed by this project – The PA Toolkit is available to all participating facilities. This Toolkit is generalisable to all residential aged care facilities and production for a larger audience is possible.
- Further development of the supporting educational resources for the RAC EoLCP would enhance implementation.

6 References

1. AIHW 2008 Residential aged care services in Australia 2006-07: a statistical overview. Aged Care statistics series 26 No. AGE 56. Canberra:
2. Maddocks I, Abbey J, Pickhaver A, Parker D, DeBellis A, Beck K. 1996 Palliative care in Nursing Homes - Report to the Commonwealth Department of Health and Family Services
3. Maddocks I, Parker D, McLeod A, Jenkin P. 1999 Palliative care nursing practitioners in residential aged care facilities - Report to the Department of Health and Family Services
4. Avis M, Greening Jackson J, Cox K, Miskella C. 1999 Evaluation of a project providing community palliative care support to nursing homes. *Health and Social Care in the Community*, 7(1):32-38.
5. Froggatt K, Poole K, Hout L. 2002 The provision of palliative care in nursing homes and residential homes: a survey of clinical nurse specialist work. *Palliative Medicine* 16: 481-487.
6. Parker D, Grbich C, Brown M, Maddocks I, Willis E, Piller N. 2003 A palliative approach or specialist palliative care? What happens in Aged Care Facilities for residents with a non-cancer diagnosis. *Journal of Palliative Care* 21(2):80-87.
7. Abbey J, Parker D, Yates P, Douglas C, Edwards H. 2007 A structured palliative approach for people with dementia. Report to the Prince Charles Hospital Foundation.
8. Reymond L, Israel F. 2008 The End-of- Life Care Pathway project. DoHA.
9. Veerback L, van Zuylen L, Swart S, van der Mass P, de Vogel-Voogt E, van der Rijt C. 2008. The effect of the Liverpool Care Pathway for the dying. *Palliative Medicine* 22:145 - 153